



Transforming Your Care

Vision to Action

**A Post Consultation Report
March 2013**

Chairman and Chief Executive's Foreword

Transforming Your Care is a challenging, yet vital, journey for the health and social care system in Northern Ireland. In October 2012 the Minister launched the *Vision to Action* consultation as a major step in the implementation of *Transforming Your Care*, and asked the Health and Social Care Board to lead the consultation process.

We are delighted that so many people became involved in the consultation, either through attendance at our NI wide events, through social media or by sending us their views. The HSCB received 2242 responses representing the views of many more organisations and individuals. We would like to say thank you to everyone who got involved in any way.

As a Board we are committed to the creation of a successful health and social care service which needs to be based on open and frank debate, and we see the emails, letters, reports, questionnaires and personal contributions as informing that ongoing debate. Whilst this report presents the formal outworkings of the consultation process, the HSCB will ensure that the information it has received will continue to be used to inform how we commission and deliver health and social care services in the future.

We have listened to the responses and a very strong message during the analysis is the clear recognition of the need for change. *Transforming Your Care* said 'no change is not an option'. Respondents to this consultation clearly agree. This consensus is reassuring and provides a strong foundation on which to plan change.

Most of what was said centred on how to implement *Vision to Action* and make it a reality. Many of the comments you made were focussed on critical themes in making change successful and sustainable. In this regard, there were some concerns over timing, resources, capacity and continued local engagement.

The HSCB considers this document demonstrates the consultation exercise was thorough and successful. This report will now be presented to the Minister. In due course he will indicate the specific steps to be taken on foot of the responses received.



John Compton
Chief Executive
HSCB



Dr Ian Clements
Chair
HSCB

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Alternative formats

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For an alternative format please telephone 028 9055 3790 (for text phone preface with 18001), or email tycconsultation@hscni.net

Executive Summary

June 2011

Minister for Health, Social Services and Public Safety, Edwin Poots MLA, asked for an independent **Review of Health and Social Care (HSC) in Northern Ireland**

Dec 2011

Report of the review was published – **Transforming Your Care** – with 99 proposals for change across a range of areas

July 2012

Draft Population and Strategic Implementation Plans published on how the Health and Social Care Board (HSCB) proposed to make service changes in response to the TYC Report

October 2012

The Minister launched **Transforming Your Care: Vision to Action** - setting out proposals for key service changes. The HSCB led the consultation process on behalf of the Minister including a household leaflet and range of public and stakeholder meetings.

January 2013

The **Transforming Your Care: Vision to Action** consultation period finished with 2242 responses received by the HSCB

March 2013

Analysis and consideration of the response to the consultation completed, and **Vision to Action Post Consultation Report** published

Transforming Your Care



Overwhelmingly the TYC Review was about making changes which would have the greatest beneficial impact for patients, users and carers, and about ensuring we have a safe, resilient, high quality and sustainable health and social care system for the future.

There is much to be proud of in our health and social care but there is a stark reality ahead mainly due to

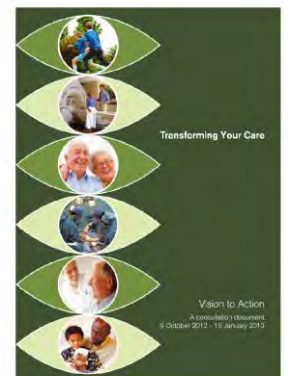
population change and growth in demand. Change is inevitable. TYC presents a managed change.

Transforming Your Care proposes a reshaped model of care with the individual at the centre to improve the health and wellbeing of people by

- **promoting** good health decisions,
- **preventing** ill health in the first place,
- **achieving** better outcomes when ill health does occur &
- **enabling** people to live healthily and independently for as long as possible.

Vision to Action

The consultation document published in October 2012 set out the strategic way forward, focussing on the key service changes, to take forward the TYC proposals over the next 3 to 5 years. It was important to bring existing and new change initiatives into a managed programme of transformation – one that focussed on a single vision.



We set out to be as clear and transparent as we can at this early strategic stage, whilst understanding that further consultation on specific changes will be needed as we move forward.



As part of the consultation, a leaflet was sent to every home in Northern Ireland, public and special interest group meetings were held across the region, and social media was used to engage with the public. Respondents were encouraged to contact us and respond in a number of ways, and by 15 January 2013, 2242 people or organisations had done so.

	Free-form letter	Questionnaire	Standard letter responses	Totals
Organisation	148	66	-	214
Individual	96	188	1744	2028
Total	244	254	1744	2242

In the main, responses were extremely considered and we would like to **thank everyone** who came to one of our public meetings, or a special interest group meeting, and to everyone who sent us their views.

These are critical to informing decisions about the way forward and about how we implement Transforming Your Care.



Most of the responses specifically addressed the proposals we made and / or the questions we asked. However it is also very important to recognise that some respondents also made comments on wider Health and Social Care service issues, or areas for policy and legislative discussion.

Whilst these comments are very important, some are outside the scope of this consultation, as they relate to wider government policy which is beyond the remit of the Health and Social Care Board. None the less we are committed, to ensure that these are passed on to the appropriate agencies.

What people told us

Overall there was strong support for change, for the TYC model and for the proposals we made.

Against this backdrop of strong support for the vision within TYC, many of the respondents commented on those aspects which would, in their view be most critical in achieving the aims to which TYC aspired. Many of the responses referred to in this document talk about the translation of the Vision into Action and how this can best be

done to the benefit of patients, users and carers. We believe there is a strong foundation upon which to plan changes.

‘Doing nothing is simply not an option’
97% of people believe that our health and social care services need to change to promote health and wellbeing

“It seems clear that health and social care services must evolve in response to; demographic changes, disease prevalence, changing social models, new care options.”
– *Individual Response*

In considering the consultation responses, it became apparent that there were five key overarching messages which will be important in how we take TYC forward:

1. The need to ensure that investment is focussed on making change happen, and that alternatives are in place and working effectively before change occurs to current services
2. A focus on how we support carers as a key partner in care provision
3. Support for staff who are the key enabler to implementing TYC
4. Importance of engaging with the voluntary and community sector in designing services and in developing their capacity to be key partners in the delivery of TYC
5. Need for greater cross governmental / agency working to address health inequalities and be more 'joined up' in our plans for implementation

Critical overarching themes from what people said about the implementation of Transforming Your Care

Alternatives in place

Respondents often highlighted a need for assurances that investment will be focussed on making change happen, and that alternatives will be in place and working effectively before change occurs. There is already a commitment to having a structured and sensible implementation of the TYC proposals as set out in *Vision to Action*, and people wanted this to be delivered upon. This includes ensuring that new or different services must, and will, be developed and working well before we step down other parts of the service.

Voluntary & Community Sector

Many respondents mentioned the opportunities that could be gained from engaging with the Voluntary and Community sector in a different way. They have a unique contribution to make in terms of innovative ideas for service design and delivery, and have a role in engaging with service users. It was recognised that building capacity and capability in the sector is required.

Carers

Many respondents stressed the importance of carers in our health and social care system. They said we need to be better at identifying carers, assessing their needs and putting resources in place to support them, particularly in the context of 'care closer to home'. The provision of flexible, appropriate respite and involving carers when planning and designing services were seen as particularly vital.

Workforce

Many people mentioned the workforce as the key enabler to success. With the movement of services from hospitals to home and community settings, respondents highlighted the need for effective workforce planning so that sufficient skills and resources are where they are needed. Appropriate investment in training and skills is vital to support the workforce.

Inter-governmental working

A number of respondents believed that statutory bodies should work closer together when planning and delivering public services, including welfare, community services, transport and housing, in order to tackle health inequalities.

This document sets out the summary and analysis of the responses we received for each of the sections in the *Vision to Action* document. This includes statistics as well as comments that people made, either in their written response or at meetings with us.

We have been open about the questions or concerns people have raised, even when there is widespread support for a proposal. At the end of each section, we highlight specific actions we believe will be particularly important as a result of what we have heard, subject to the approval of the Minister. We also make an overarching commitment that the detail in the responses we received will be ‘fed forward’ into our implementation processes over the next 3 to 5 years.

Population Health and Wellbeing	Strong support for greater focus on early intervention and prevention of ill health. The need for a whole system approach to tackling health inequalities was highlighted, as in the “Fit and Well – Changing Lives” Public Health Strategic Framework recently out for consultation.
Delivering services at home and in the community: Integrated Care Partnerships	When asked whether ICPs could make a positive contribution to delivering care closer to home, 89% agreed. In general, there was a qualified welcome for the introduction of Integrated Care Partnerships, focusing on frail elderly and those with long term conditions. More information on how these will work in practice is needed, and ensuring that there is involvement and leadership from across health and social care professionals, voluntary and community sector, service users and their carers.
Older People	Providing care closer to home for older people was very well received and 73% of respondents agreed with the proposals. Respondents felt it important to help support older people to live as independently as possible for as long as possible where it is safe and appropriate to do so. There were some concerns highlighted about domiciliary care provision and proposed closure of statutory residential homes. We propose that investment in alternatives, which is enabled by closure of some statutory residential homes is the most appropriate way forward as we did not receive any compelling evidence to the contrary.
Long Term Conditions	There was a welcome for the proposals for those with long term conditions – 94% felt it would be helpful to have more information and education to encourage self-management, and 89% thought more use of technology could reduce avoidable visits to hospital. We recognise that self-management and increased technology, is not appropriate for everyone.
Palliative and End of Life Care	There was strong endorsement for implementation of the palliative care and end of life proposals – 95% agreed the proposals would support people to be cared for in a place of their choice. Some challenges were outlined by professional groups including the need for greater clarity on roles and accountabilities, and the need for awareness and education for staff across the different sectors (statutory, independent, and voluntary and community), and the public.
Mental Health	Overall 77% of respondents agreed with the proposals for mental health services. There was strong agreement for the continued implementation of Bamford proposals, with more services being provided in the community. The issue of the placement of the second mental health inpatient unit in the Western area was more emotive, and in this document it is suggested that further consideration is needed on this matter.

Learning Disability

Again the consensus was in favour of the continued implementation of Bamford recommendations including resettlement of those currently living in long stay institutions, with 88% of respondents agreeing with proposals. People wished to see increased progress in this area. A particular focus was placed on a need for age-appropriate services for people with learning disabilities, including how people transition from child to adult to older people's services.

Physical Disability & Sensory Impairment

The majority of responses received demonstrated support to progress with the proposals outlined (92% agreed with the proposals) whilst making suggestions for how services could further be improved, notably the need for specific action plans. Respondents felt that it was crucial that people with physical disability and sensory impairment continue to be effectively engaged in the design and implementation of services.

Family & Child Care

There was strong agreement with the proposals with 92% agreeing. Respondents fully supported keeping children within their families and felt that an emphasis on early intervention and prevention would facilitate this, specifically with the introduction of Family Support Hubs. There was wide agreement for increasing the number of foster parents and an overwhelming support for improving child and adolescent mental health services (CAMHS).

Maternity & Child Health

There was positivity around the normalisation of birth from respondents and a welcome for the focus on improving antenatal and early parenting education. Overall 78% agreed with the proposals. Some respondents were concerned about the use of midwifery units, however most were positive when they were placed on site or in close proximity to consultant led obstetric care. There was a welcome for the Family Nurse Partnership Programme with respondents calling for them to be extended regionally.

Acute Care in Hospitals

As expected comments on this section were often in relation to specific proposals or localities. Overall 66% agreed with the proposals with recognition of the need to review acute hospital configuration and investment in specialties was warmly welcomed. It is important to emphasise that the proposals would not result in a closure of an acute hospital but that all of our current hospitals would work in a network with its neighbours to make best use of the resources we have across Northern Ireland. Clinical groups were supportive, as were patient and user groups so long as outcomes and quality of care can be assured. The use of clear and transparent evidence is important in this regard.

The issue that attracted the largest number of responses (around 70% of the total response) was about Causeway hospital. These letters promoted the need for retention of full general hospital services at Causeway hospital and were supportive of the proposal to do an Options Appraisal about the future management arrangements for Causeway. Having considered all responses on this matter, we believe that the Options Appraisal should take place and should include community services in the Causeway locality.

Increasing links with Republic of Ireland & Great Britain

This proposal was very well received, 92% agreed with the proposals. Respondents felt that increasing links would ensure that patients can benefit from the most up to date treatment and knowledge, reduce waiting times for certain procedures with better outcomes for the patient. A small number of respondents raised concern around the pressures that travelling for treatment can place on patients and families.

Equality & Human Rights

Of those that answered these questions, 74% thought proposals would not have an adverse impact on equality groups, and 80% were unaware of any evidence of an adverse impact on opportunity or good relations. A small number of respondents, particularly from organisations sought a full Equality Impact Assessment (EQIA) on TYC as a whole. EQIAs will be undertaken as specific service changes are brought forward for implementation. Through our discussions with the Equality Commission and Human Rights Commission, we remain committed to a rights based approach to transformation and there was strong support for this in consultation responses.

Conclusion

The HSCB would like to repeat our thanks to all those who took part or provided their views during the consultation on *Vision to Action*.

We conclude that there is widespread recognition of the need for change in our health and social care system, strong support for the model that Transforming Your Care puts forward, and for the proposals for change which will turn that model into a reality. It is now critical that there is certainty about the way forward and about how TYC will be implemented. In doing so, we need to have an unrelenting focus on delivering high quality and compassionate care to deliver better outcomes for patients, service users and their carers.

What this consultation has demonstrated is that people want to be involved in the debate about how we develop health and social care services and how we can make the best use of the resources we have.

This report is the HSCB response to a request from the Minister to undertake consultation on the proposed service changes arising from the Transforming Your Care report published in December 2011. In our view it provides a strong foundation for the way forward and implementation of the *Vision to Action* proposals, having due regard to the feedback received during this consultation.

Subject to the Minister's approval to proceed, the HSCB, working closely with our colleagues in the Public Health Agency, Trusts and elsewhere, will put in place the detailed implementation plans to take forward the service changes set out. On-going consultation and engagement with the general public, and organisations involved in the health and social care sector will be critical to achieve TYC's objectives and deliver better outcomes for all. We look forward to continuing the debate and conversations opened during this consultation, over the coming years.

Part 1. Introduction and Background

1.1 The Review of Health and Social Care

In June 2011, the Minister for Health, Social Services and Public Safety, Edwin Poots, MLA, asked for a Review of the Provision of Health and Social Care (HSC) Services in Northern Ireland. The Review was to provide a strategic assessment across all aspects of health and social care services, examining the present quality and accessibility of services, and the extent to which the needs of patients, service users, carers and communities are being met. Crucially it was to bring forward proposals for the future shape of services and provide an implementation plan.

The Review team was asked to ensure that available resources were used to best effect, and this continues to be a major driver for *Transforming Your Care* (TYC).

Overwhelmingly the Review was about making changes which would have the greatest beneficial impact for patients, service users and carers, and about ensuring we have a safe, resilient, high quality and sustainable health and social care system for the future.

There is much to be proud of in our Health and Social Care system but there is a stark reality ahead. We have a growing and ageing population and those with disabilities are living longer. While these are facts to celebrate, this, together with:

- the rising cost of technologies and drugs;
- lifestyle issues such as obesity and alcohol; and
- family structures and pressures leading to rising demand for children's services

means that we need to think differently to meet the demands that lie ahead. Without change there is a growing potential for instability in the Health and Social Care system and an increasing difficulty in meeting the future needs of our citizens.

We need to prepare our services for the future, and this will mean making choices about how we want our health and social care services to be delivered, based on the best evidence.

1.2 *The Transforming Your Care: Vision to Action Consultation*

In October 2012, the Minister launched *Transforming Your Care: Vision to Action* to provide information to help all citizens of Northern Ireland to contribute to the debate on the future of our Health and Social Care. It set out the proposed service changes, within and aligned to existing policy frameworks, in response to the TYC Report published in December 2011.

This document was based on the draft Population Plans which were developed by Local Commissioning Groups, with input from Health and Social Care Trusts, to reflect local needs, and a draft Strategic Implementation Plan which gave a wider Northern Ireland overview. All of these draft documents were originally published in July 2012 and were published again in October 2012 following a period of quality assurance.

The Minister for Health, Social Services and Public Safety, Edwin Poots MLA asked the HSCB to conduct a period of public consultation on the proposals for service changes set out in the *Vision to Action* document, and the draft plans. Further detail of the consultation process undertaken is set out in Part 2 of this report.

This Post Consultation Report is the HSCB’s response to that request, and sets out a summary and analysis of the 2242 responses we received to our public consultation, and provides information on what we propose to do as a result of what we have heard, subject to ministerial consideration and decision.

In the main, responses were extremely considered and we would like to thank everyone who came to one of our public meetings, or a meeting held by an interest group, and everyone who sent us their views. These are critical to informing decisions about the way forward and about how we implement TYC.

Most of the responses related specifically to the TYC model, the proposals in *Vision to Action* and / or the questions posed. However it is also very important to recognise that some respondents also made comments on wider Health and Social Care service issues, or areas for policy and legislative discussion.

Whilst these comments are very important and some have relevance to the success of TYC, it is also acknowledged that some are outside the scope of this consultation as they may relate to wider government policy which is beyond the remit of the Health and Social Care Board. We are committed, however to ensure that these are captured and will ensure these comments are shared with the relevant body.

1.3 An overview of what Vision to Action proposed

The *Vision to Action* consultation document outlined how the new model of care is to be organised with the individual at the heart of the model, rather than the institution or the hospital.

The document broadly covered four key themes:

1. Individual - We looked at what we can do to keep individuals healthy and how we could help you improve your own health and wellbeing.

2. Delivering health and social care services as locally as possible - We proposed to make home or the community the hub of care, reducing the need for avoidable visits to the hospital.

3. Safety and Quality of acute care in hospital settings - We highlighted the need to ensure that emergency care and planned specialist care provided in hospitals is safe and sustainable and meet the best quality standards.

4. How we can collaborate better with our neighbouring jurisdictions - In some cases the very best care may not be in Northern Ireland, where there is low volume or the treatment is very specialised.

The document summarised the key proposals for change to be considered in the context of the challenges facing Health and Social Care (HSC) in Northern Ireland. It set out, across Programmes of Care, specifically how we propose to make service changes to the model of health and social care and what it will look like.

The sections in the *Vision to Action* document were:

- 1) Population Health and Wellbeing
- 2) Delivering services at home and in the community: Integrated Care Partnerships
- 3) Older People
- 4) Long Term Conditions
- 5) Palliative and End of Life Care
- 6) Mental Health
- 7) Learning Disability
- 8) Physical Disability and Sensory Impairment
- 9) Family and Child Care
- 10) Maternity and Child Health
- 11) Acute Care in Hospitals
- 12) Increasing our links with the Republic of Ireland and Great Britain

The key desired outcomes for TYC, as described in *Vision to Action*, are:

- People will get support to stay healthy, make good health decisions or manage their own conditions.
- More services will be provided locally with opportunities to access specialist hospitals where needed.
- More people will be cared for at home, where it's safe and appropriate to do so.
- People will have more choice and greater control over the types of services they are able to access.
- Investment in new technology will help people stay at home or receive care locally rather than in hospitals.
- Doctors, nurses, social workers and everyone providing care will work together in partnerships to help keep people healthy and prevent them going to hospital when that's not necessary.
- Any decisions about how we do things should be driven by evidence that it will be better for patients and users, and be better quality.
- Everyone working in health and social care services will be supported in helping to make the changes set out in TYC.

1.4 *How is this document structured?*

The *Vision to Action* document focused on the proposed service changes which we anticipated would have the greatest impact on shaping our health and social care services of the future, and be as clear and specific as possible about what this means for citizens. Similarly this document focusses on those aspects which have most impact on the implementation for TYC.

We found many responses provided significant and comprehensive views on both the proposals and on current health and social care services. Also some provided additional detail and evidence, often relating to their specific area of interest. It would be impractical to make individual responses available or to respond to each individually. We are committed to putting in place a process within the HSCB, working together with the Public Health Agency, to ensure that detailed responses are included in the commissioning and delivery of services going forward.

In this report, we draw out the themes from the responses, and in doing so wish to be as open and transparent as possible, whilst making this document as accessible, rather than overly long or complicated. We have therefore been open about the concerns people have raised as this is where we believe constructive debate can be had, even when there is widespread support for a proposal, or only a relatively small number of people have raised the concern. We make an overarching commitment to take account of all responses as we move forward. In this document, having considered all the consultation responses, we comment on the areas we think should be particularly highlighted as key for implementation on the proposed service changes. These HSCB comments are at the end of each section. All such comments and proposed response to what we have heard are subject to the Minister's decision to proceed.

We are also happy to discuss the outcome of this Post Consultation Report with any respondent or stakeholder during the course of the implementation.

In this Post Consultation Report we continue to use the structure around 'Programmes of Care' that was employed in the TYC Report, the draft Plans and in the *Vision to Action* consultation document. We also found there to be a series of overarching themes which impact on all Programmes of Care which would benefit from separate discussion.

The structure of this report is set out below:

In the next section, **Part 2**, we describe the consultation process and methods and the profile of respondents.

In **Part 3**, we address the need for change and the future model of care as proposed by TYC.

In **Part 4**, we draw out the key overarching themes identified from consultation responses, and provide our response to this in terms of actions we propose should be taken as a result of what we have heard.

In **Part 5**, we focus on each of the 12 sections in the *Vision to Action* document and questionnaire, plus Equality and Human Rights. Each of these sections will set out the quantitative results from the consultation questionnaire, provide a summary of the qualitative responses and comments made to us, and finally indicates how the HSCB proposes to respond in terms of the implementation of TYC.

In **Part 6**, we look at the responses and comments received about Part 5 of *Vision to Action* (Supporting these changes to happen). This looked at the possible implications for our workforce and organisation, for our finance, for technology advances, and for how we procure services from organisations outside the HSC family. Whilst specific questions were not asked on these aspects (and therefore we do not have quantitative results) many respondents have commented on these areas, and these will be summarised in this section.

The remainder of the document sets out what happens next.

Part 2. The Vision to Action Consultation Process

2.1 Overview

This section provides further information on the design and operation of each component of the consultation process, and information on the profile of responses.

The stated aim of the consultation was to be clear and transparent about what we are doing in a co-ordinated way rather than introducing piecemeal changes which people cannot see or fully understand. It was to focus on those areas which would see the most significant change and be as specific and explicit as possible, to enable everyone to contribute to the difficult choices ahead.

In achieving this aim, it was important to make the consultation as accessible as possible using all established methods of engagement, such as printed materials in a range of formats, up-to-date online information and face-to-face contact through a variety of meetings and events, as well as embarking on new channels of engagement through social media.

2.2 Promotion and Accessibility of the Consultation Exercise

There were a number of modes of contact open and promoted to those who wished to contact the Health and Social Care Board (HSCB) Transforming Your Care (TYC) Team or respond during the consultation exercise. This multi-channel approach included:

- Phone (including text phone)
- Post
- Email
- Fax
- Website (www.tycconsultation.hscni.net)
- Online questionnaire
- Downloadable forms and documentation
- Facebook (facebook.com/tycconsultation)
- Twitter (@tycconsultation)



The *Vision to Action* document was made available in the following formats:

- Hard copy (circa 2000 were distributed)
- Downloadable
- Braille
- Audio
- Easy Read
- Large Print

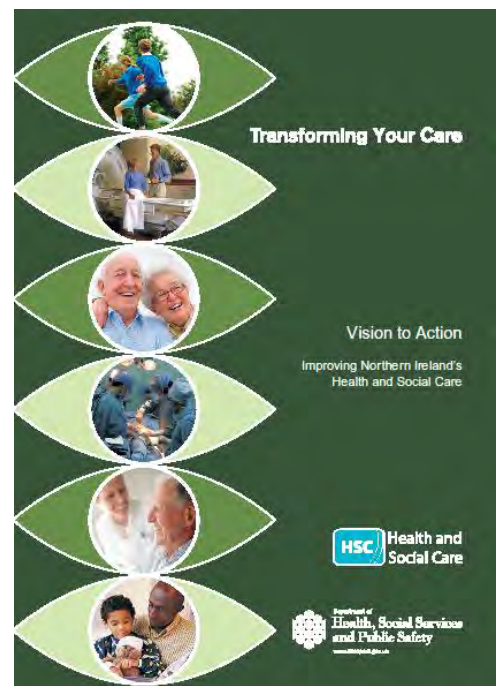
A Questionnaire was also produced alongside the *Vision to Action* document, to support those who wished to respond to the questions posed in the document. This was available in the following formats:

- Online and downloadable (either pdf or MSWord)
- Hard copy with Freepost envelopes (A5 booklet versions were made available at all meetings and sent out to those who requested them – in total 610 of these were distributed)

To ensure that everyone in Northern Ireland had the opportunity to read some introductory detail on TYC, the consultation exercise, and the ways they could get involved, an information leaflet was delivered to every home in Northern Ireland in autumn 2012. This leaflet provided details on the consultation exercise and also gave contact numbers, website address, and links to Twitter and Facebook.

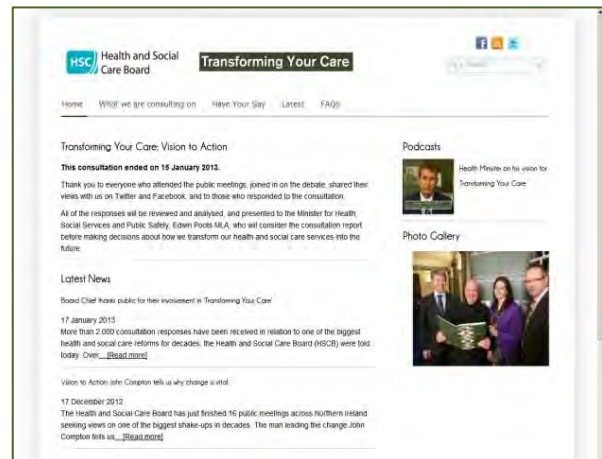
The leaflet was made available in various formats:

- Hard Copy and downloadable
- Audio (including 1800 sent to registered blind people on RNIB's database)



The website developed for the consultation included the following:

- Information on TYC
- All documentation including draft Population Plans, draft Strategic Implementation Plan and Equality Screening
- Frequently Asked Questions.
- Four Podcasts on aspects of TYC
- Online Questionnaire and contact channels



The table below sets out usage information on these channels of engagement.

Communication and Contact Activity	Number of contacts
Household leaflet	758,780
Hard Copy documents distributed	2000 circa
Requests for alternative formats ¹ of consultation document	8
Public Meetings	16
Numbers in attendance at public meetings	533
Stakeholder Meetings	26
Numbers in attendance at stakeholder meeting	280
Website Unique Visitors ²	6,258
Website Total Hits ³	26,140
Facebook likes	40
Twitter Followers	145
Tweets/ Interactions	182 / 156

Finally, a number of activities were undertaken to raise awareness of the consultation exercise, including

- Media briefings, press releases and articles in local and regional press at the launch and during the period.

¹ Alternative formats include: Braille, Audio, Large Print, Easy Read

² Unique visitors is the number of unduplicated (counted only once) visitors to the website during the consultation

³ Total number of times pages were viewed during the consultation period

- Adverts placed in local press providing details of the public meetings being held across Northern Ireland.
- John Compton, Chief Executive of the HSCB, wrote to over 500 individuals and organisations on our stakeholder list at the launch of the consultation and again to publicise the public meetings.
- A number of stakeholders were contacted directly to encourage response and offer focussed meetings or support to respond.

2.3 *Public Meetings*

As part of the public consultation, the HSCB led a series of public meetings across Northern Ireland, working closely with the Local Commissioning Groups and the Trusts for each area. There were 16 public meetings held in total and these are set out below, together with the registered attendance at each. At some meetings there were a number of attendees who declined to register at the meeting. Further details of where each was held and a summary of the format used are set out in Annex 1.



Pictured at the Lisburn TYC public consultation meeting.

Area	Locality	Attendance
Belfast	Belfast 1	31
	Belfast 2	18
	Belfast 3	18
South Eastern	Lisburn	24
	Down	27
	Newtownards	25
Northern	Coleraine	80
	Newtownabbey	35
	Magherafelt	36
	Ballycastle	23
Southern	Banbridge	55
	Armagh	22
	Newry	35
Western	Derry	26
	Omagh	45
	Enniskillen	33
	TOTAL	533

Each meeting ran to a similar format with a standard presentation, a series of TYC podcasts (short videos) and Q&A debate. An independent facilitator supported each of the public meetings, which was intended to ensure that all participants were enabled and supported to have their say and also that the public could be reassured that the process was open and transparent. More detail on the format of each meeting is in Annex 1.

The comments, views and queries raised at the Public Meetings have been included in the qualitative analysis undertaken to inform this document.

At many of the 16 public meetings local issues often took centre stage. At the Coleraine meeting, questions focussed on the future of the Causeway Hospital, and the proposed move of management to the Western Health and Social Care Trust. In the Tara Centre in Omagh mental health services in the area was emphasised in the public's questions. Often the future of the local hospital or local residential home was raised as a question by an attendee.



Pictured at the TYC public consultation meeting held in Armagh

Questions and comments raised in these meetings covered a wide range of issues across all of health and social care. However as the meetings progressed a number of themes emerged:

- The vital work of carers and their need for support was raised in all of the meetings, with access to respite seen as needing improvement.
- Representatives from the local workforce and trade unions were present at a number of public meetings. As a result staff concerns were raised, as were concerns around health and social care privatisation.
- A number of attendees were unsure about what an ICP would be and how it would operate, and requested clarification on their function and structure.



Members of the deaf community from the Newry and Mourne area chat to John Compton, HSCB Chief Executive, at the Newry public meeting.

2.4 *Meetings with organisations, groups and agencies*

In addition to public meetings which were open to the general public and interest groups, there were some specific engagements with organisations such as NI Council for Voluntary Action (NICVA), senior clinical staff in Trusts and Staff Side partners. Annex 2 provides a list of these meetings.

Some organisations (such as British Medical Association, Royal College of Nursing, Age NI, Barnardos and Carers NI) held their own workshops and meetings to inform their collegiate response. We have not captured the numbers attending these meetings.



Pictured at a meeting with NIAMH (Northern Ireland Mental Health Association) during the consultation period.

Across these meetings, the key message was one of support for the need for change and the vision and principles contained in TYC, as well as widespread support for the proposals. A significant proportion of debate centred on how implementation can ensure that the outcomes can be achieved, and those factors considered critical in doing so.

Due to the nature of these engagements, which were often focussed on specific interest areas, it would not be practical to summarise themes. These form part of the qualitative analysis within the remainder of this document.

2.5 *Use of electronic communications & social media*

A number of electronic communications and engagement channels were set up specifically for the purposes of *Vision to Action* consultation. We have evaluated the use of these channels and it is the view that social media and electronic communications were an extremely useful and effective way to spread information and raise awareness about the consultation, and we found it started to host debates about the TYC proposals, but that more could be done in future to use these means as a way of capturing the views and opinions of groups and the general public and to promote debate.

There were over 160 comments/interactions from followers. Those commenting included politicians, voluntary and community sector, charities, campaigners, professional bodies and individuals. The majority of comments were positive from followers with many forwarding information about the TYC public meetings and key proposals to their own social media followers inviting them to respond to the consultation.

“Good debate on shifting balance of care from hospital to community setting” Attendee at TYC Public Consultation meeting in Belfast

*“Every organisation I have spoken to says TYC is the correct way to go.”
MLA*

“Don’t forget to have your say on the future of health and social care in NI.” Junior Doctor

Some comments received however, indicated concerns regarding TYC costs and administration, privatisation, support for carers and some personal comments on services in Mid Ulster and the Northern HSC Trust.

“Who is going to pay for this? What is the projected cost of administration alone?” Campaign group.

“Is the Mid Ulster area being by-passed again for public meetings surrounding TYC?” Campaign group.

“Carers need recognition and protection under the proposed health reforms.” Charity

2.6 Compliance Assessment of Consultation process and data analysis

As part of the consultation process, the HSCB engaged the Consultation Institute to provide a compliance assessment to:

- Conduct an independent compliance assessment of data analysis methodology, both quantitative and qualitative
- Assess the quality control mechanisms in place and determine if they have been adhered to

- Assess whether the presentation and reporting of the material is in an acceptable manner, to comply with The Consultation Charter in respect of feedback to respondents and others, and ‘feed-forward’ to decision-makers.

They were able to provide assurance of our practice and commented that the data analysis methodology was “conscientiously planned and executed”, and the quality control mechanisms were “these have been well considered and executed.”

The Consultation Institute have awarded the HSCB a Certificate of Best Practice and endorsed our approach to these aspects of the consultation as a quality assurance measure.

2.7 Profile of Responses to the Consultation

A total of 2242 responses were received in written form, including letters, emails and completed questionnaires.

Respondents had a number of options for communication if they chose to make a written response. They were able to complete a questionnaire online via the website, could submit an email or hard copy of the questionnaire or write their response in a letter or an email (what we are calling ‘free-form’ responses).

Respondents included individual members of the public, voluntary and community or interest group organisations or groups, local Councils, public sector organisations such as Trusts and other public bodies, Trade Unions and Professional bodies, and political representatives and parties.

Both organisations and individuals chose to submit their views via the questionnaire and through free-form responses. A considerable number of individuals also chose to make their views known through the use of a generic letter format with consistent content provided to them – often this took the form of standard text with individuals’ signature and contact details. We have called these ‘standard letter responses’.

We were able to extract quantitative data from the questionnaire responses and this forms the basis of the graphs and statistics you see in this report. We were able to extract qualitative data from all three types of response: free-form, questionnaire and standard letters.

The breakdown of the type of response is shown in the table below.

	Free-form letter only	Questionnaire formed basis of response (may also have provided free-form views alongside)	Standard Letter Responses	Totals
Organisation	154	61	-	215
Individual	90	193	1744	2027
Total	244	254	1744	2242

2.7.1 Organisational Responses

Of the 2242 responses, 215 were from organisations, groups or political representatives, across questionnaire or free-form formats (or some organisations submitted both but this is counted as one submission). A breakdown of the organisational type is set out in the table below. A full list of the organisations who responded is in Annex 4.

Type of respondent	Number of responses received
Voluntary and Community (3rd) sector (including Interest Group) ⁴	107
Public / Statutory Body (including Trusts and ALBs)	26
Professional Body	20
Council	19
Pharmaceutical	12
Political (Group)	9
Political (Individual)	8
Staff Side Organisation	7
Independent / Commercial Sector	3
Professional Body and Staff Side Organisation	3
Academic	1
Grand Total	215

⁴ Please note that when referring to the Voluntary and Community or 3rd sector, we recognise that this is wide and varied sector of organisations, ranging from interest groups that come together to represent people's views about an issue through to large organisations who operate social enterprises, providing services or advice on a not-for-profit basis. There are also 'umbrella' groups who seek to represent the views of a range of members or user groups. It is also recognised that some organisations will span a number of roles. For the purposes of this document we use the acronym V&C sector to refer to this heterogeneous group or bodies, organisations, and interest groups.

2.7.2 *Standard letter formats*

The majority of respondents opted to write letters, many of which were in a standard format relating to a particular issue. The main issues that attracted this form of response were

- Proposals around Causeway Hospital, for which there were three standard letters, which combined made up 1538 letters.
- The Irish Congress of Trade Unions produced a standard letter for use by their members who wished to use this format and 141 such responses were received.
- Two organisations which expressed views about Residential Care facilities also produced standard letters: 33 standard letters were received from Friends of the Roddens (with signatures from 401 people), and 29 standard letters were received from Friends of Lisgarel.
- The Oyster Peer Support Group also sent 3 responses using a standard letter format.

The total responses received in some form of standard letter style were 1744 across the various areas of interest listed above. Copies of these can be found in Annex 5.

2.7.3 *Questionnaire responses*

In total, 254 completed questionnaires were submitted, either online, via email or on hard copies sent in by post. This included responses from individuals, public sector organisations, voluntary and community sector groups, the commercial sector and professional bodies. As the questionnaires requested a certain amount of demographic information from respondents, where this was completed it has been possible to provide some limited breakdown on the respondents. It should be stressed that not all questionnaire responses provided demographic information, but what was submitted is summarised overleaf.

Type of respondent	Number of responses received
Individual	188
Community and Voluntary (3rd Sector Including Interest Groups)	35
Public / Statutory Body (including Trusts ALBs)	11
Pharmaceutical	6
Council	4
Independent / Commercial Sector	2
Political (Group)	2
Political (Individual)	1
Professional Body	4
Academic	1
Total	254

In the questionnaire we asked a number of demographic questions. These were not mandatory. Where respondents have provided this information it is shown below:

Are you...	Number of respondents
Under 65	118
Over 65	46
A Carer	40
Disabled	20
A Parent	37
Other	57

Please note the total does not add up to 254 as respondents had the option of ticking multiple boxes

Part 3. The need for change and the Transforming Your Care model of care

3.1 What Vision to Action said

The *Vision to Action* document sets out compelling reasons why we need to change. This is not a criticism of what we have now, but recognises that with the challenges ahead, the way we do things now is not going to work well in the future.

The key factors driving why we need to change are:

- 1. A growing and ageing population:** In Northern Ireland we have one of the fastest growing populations within the UK. The Northern Ireland Statistics and Research Agency (NISRA) has projected the NI population to rise by 8% by 2025 and project that over the same 15 year period, the numbers of people aged 65 and over will increase by 42%. Compared to 2010, it is projected that the over 85 population will have doubled by 2027.
- 2. Increased prevalence of long term (chronic) conditions:** There are increasing numbers of people with chronic conditions such as diabetes, respiratory problems, stroke and obesity. Also, individuals often have multiple conditions and sometimes our system could be better co-ordinated in how we deal with this.
- 3. Increased demand and over reliance on hospital beds:** it is estimated that the demand for services could grow by 4% per year until 2015. If services continue to be delivered as they are currently this could mean 23,000 extra hospital admissions, 48,000 extra outpatient appointments, 8,000 extra nursing home weeks, and 40,000 extra 999 responses. Simply providing more beds will not address these challenges and will not lead to improving the quality of our services.
- 4. It is getting more and more difficult to ensure clinical workforce supply** which can put pressure on service resilience. We have a dedicated and highly skilled workforce but we need to ensure we have a health and social care system that is fit for purpose for them to work in.

5. We need to have **better productivity and value for money**: the TYC Review and Report was not about saving money, it was about making best use of what we have. We can always be more efficient and get more for less by doing things differently.

The 12 key principles underpinning the approach in TYC are set out below:

1. Placing the individual at the centre of any model by promoting a better outcome for the user, carer and their family.
2. Using outcomes and quality evidence to shape services.
3. Providing the right care in the right place at the right time.
4. Population-based planning of services.
5. A focus on prevention and tackling inequalities.
6. Integrated care – working together.
7. Promoting independence and personalisation of care.
8. Safeguarding the most vulnerable.
9. Ensuring sustainability of service provision.
10. Realising value for money.
11. Maximising the use of technology.
12. Incentivising innovation at a local level.

3.2 What people told us?

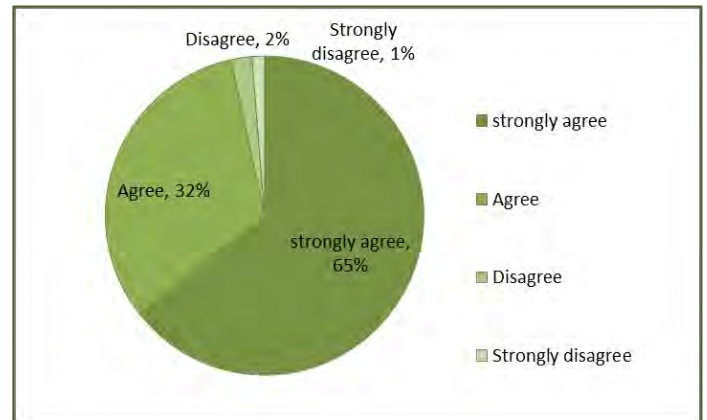
We asked five questions in this section of the consultation document:

Q1. Do you agree that our health and social care services need to change in order to meet the needs of the community and promote health and well-being through prevention and early intervention so that as much acute illness as possible is avoided?

Of the 254 questionnaire responses, 236 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **97% agreed or strongly agreed with the need for change**
- **3% disagreed or strongly disagreed**

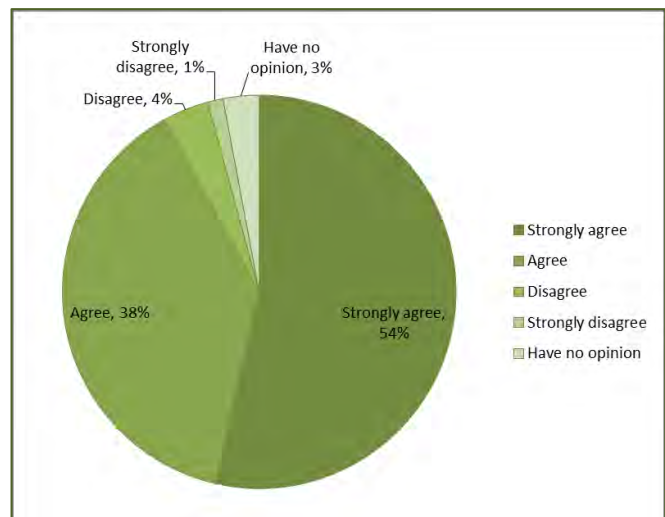


Q2. People should have control over how their assessed care and support needs should be met.

Of the 254 questionnaire responses, 237 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **95% agreed or strongly agreed that people should have control over how their assessed need should be met**
- **5% disagreed or strongly disagreed**

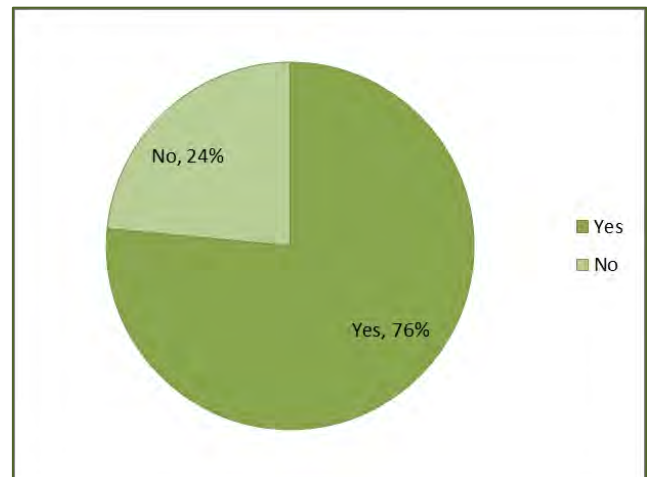


Q3. Do you feel that provision of individualised budgets and self-directed support should be more widely promoted?

Of the 254 questionnaire responses, 217 answered this question. The graph below sets out all the responses we received in percentage terms

The statistical analysis of the responses to this question show that:

- **76%** thought that individualised budgets and self-directed support should be more widely promoted
- **24%** did not agree with this statement

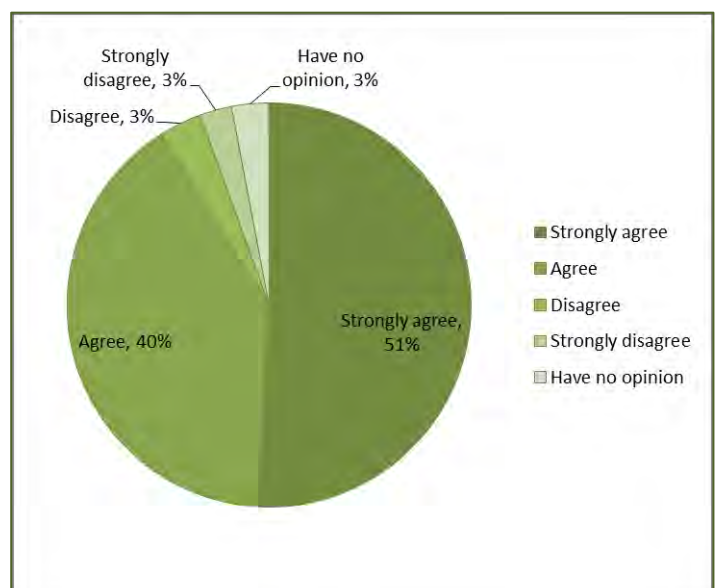


Q4. We should organise services to enable people to stay at home as long as possible or be cared for at home.

Of the 254 questionnaire responses, 234 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

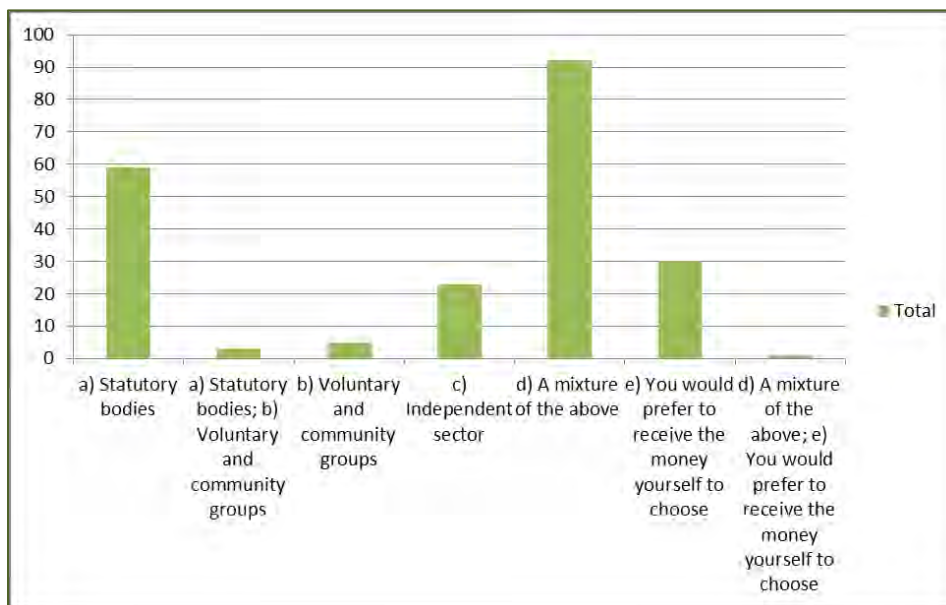
- **93%** agreed or strongly agreed we should organise services to enable people to stay at home or be cared for at home
- **7%** disagreed or strongly disagreed



Q5. Given the choice, who would you like to provide your care/support in your home?

1. Statutory bodies
2. Voluntary and community groups
3. Independent sector
4. A mixture of the above
5. You would prefer to receive the money yourself to choose

Of the 254 questionnaire responses, 213 answered this question as follows. Due to the range of responses to this question, this graph shows actual response figures, rather than percentages:



The statistical analysis of the responses to this question show that of those who answered this question (have no opinion was not an option for this question):

- The majority, **92 respondents** felt they would like a mixture of providers. **59 respondents** felt they would like statutory bodies to provide their care/ support at home.
- **30 respondents** indicated that they would prefer to receive the money themselves to choose their own **care provider**.
- Smaller numbers of **respondents (23)** stated they would like their care to be provided by the independent sector.

In addition, a considerable number of respondents provided comments on this section of the document. These are summarised below.

The need for change

The responses from the questionnaire and the free-form comments show an overwhelming recognition of the need for change across our health and social care services in order to

- meet the needs of our community; and
- promote prevention and early intervention to avoid acute illness.

This underlines the view of the Review of Health and Social Care in Northern Ireland that “no change is not an option”.

It is noteworthy that of the respondents who answered this question on the questionnaire, everyone had a clear opinion on it, as none of the respondents chose the “do not have an opinion” option for this question. Similarly many of the free-form, non-questionnaire based responses also referred to the need for change. This was consistent across both responses from the general public and organisations.

Indeed, many of the responses mentioned the growing and ageing population and the current economic situation as key reasons why change is needed.

*“The service was designed more than 60 years ago with a population that had a different age profile, life expectancy, much lower expectations of the service and vastly different access to communications and transport”
– Individual Response*

“We acknowledge that the current situation regarding the health service in Northern Ireland is untenable and believe there is a willingness within the medical profession to embrace the need to do things differently. Incremental changes to the existing models of care will not be sufficient in addressing the challenges which lie ahead. It is our view that a much bolder approach is needed” – British Medical Association

*“The RCN endorses, in general terms, the commentary on the need for changes and the underlying vision, principles and objectives behind TYC”
– Royal College of Nursing*

It was also highlighted by a number of respondents that there is a need for increased productivity within health and social care and a need to demonstrate greater value for money.

There was a strong message that while there is support for change, that change must be properly managed, measured and resourced, and implemented with engagement from HSC staff and stakeholders:

“A compelling case for change has been made. The change process must empower and enable HSC staff to make definitive care decisions for patients and clients as soon as possible in the process of engaging with patients and clients.” – Individual Response

Also, the importance of a parallel shift in resources in order to make change possible and sustainable was emphasised. This is discussed in more depth in Section 4.1 below.

There were a small number of respondents who disagreed with the need for change. Those respondents felt that the changes proposed under TYC were intended as cuts to health service funding and/ or indicated a move away from NHS core principles and a move towards privatisation of health care. Whilst acknowledging that some change is “inevitable”, one Staff Side organisation disagreed with the assertion that TYC is about “making the best of what we have” and argue for greater investment in health and social care services. One political party commented that the financial framework of TYC is flawed due to their view it is advocating *“wholesale privatisation of services”* and will not address health inequalities. Other political parties did not share this view.

In commenting on the principles underpinning TYC, a small number of respondents suggested additional principles they would like to see included.

“We further recommend that an underpinning theme within TYC should be the promotion of age equality within health and social care.”- Equality Commission for Northern Ireland.

Control over assessed care and support needs

The vast majority of respondents who used the questionnaire agreed or strongly agreed that people should have control over how their assessed care and support needs should be met. The qualitative comments and free-form responses concurred with this view. An illustrative comment was:

“Everyone is entitled to have a voice and only they know best what they need” – Individual Response

This key principle of TYC was highly supported by individuals and organisations alike, and respondents felt that this would help ensure that

people receive the care they need rather than just the care the system can currently offer. However, it was emphasised that not all patients will have the capacity or communication skills to effectively exercise choice over their care and there must be support in place and alternative arrangements for this patient group.

Support must be given to individuals and families to help them understand the choices available to them, as illustrated by the comment below:

“I feel people should have more of a choice when it comes to their care and have access to all necessary information to make informed choices.” - Individual Response

There were a small number of responses which expressed concerns about the balance of choice and control and the need for professional input to patient decision making. In addition, it was also suggested by a very small number of respondents that this proposal could result in greater inequities in care across the province.

Individualised budgets and self-directed support

Again, many respondents agreed with this principle, saying that for some people it is appropriate that they have the choice. One respondent used a personal example to illustrate this:

“My mother has no say in where she goes for respite. She is forced into a home she doesn’t like as opposed to the one she likes and goes to for day care. This in no way adheres to the principle of continuity of care or personal choice and dignity. The reason the Trust gives for this is budget.” - Individual Response

It was suggested by some respondents that the availability of individualised budgets and self-directed support gives a strong signal that service users can become active participants in their own health and social care as opposed to passive participants in the process, and that this was a positive direction.

Some of the responses in this area implied that there could be a lack of understanding of the difference between individualised budgets, self-directed support and Direct Payments. Some of the comments made indicated that their past experience of Direct Payments would influence their views on this matter. We need to get better at explaining what these concepts would mean for people in practice.

Within this context, it was emphasised that before widely promoting the provision of individualised budgets and self-directed support there need to be structures in place to ensure end users can make informed decisions about complex choices, and that issues with bureaucracy experienced by some with Direct Payment are addressed.

Some of these views and comments are also illustrated within the sections on Older People, Mental Health, Learning Disability and Physical Disability and Sensory Impairment. Some general themes were:

- There was some caution expressed about the way in which individualised budgets will be implemented and it was highlighted that lessons must be learned from their implementation in England.
- A small number of respondents felt that this approach could be too difficult to manage for many people and could be open to abuse and mis-management.
- There were some suggestions that the promotion of self-directed support and individual budgets could introduce a two tier system of health and social care.

In addition, there were a small number of queries about the regulation of care providers under an individualised budget system and also about the alternatives for those who do not wish to take up the option of self-directed support and individualised budgets.

In taking forward the proposals on individualised budgets and self - directed support we believe there is need to have a strong focus on addressing the concerns and queries to ensure a safe and appropriate process. This will allow as many people as possible to benefit from this approach and will ensure that there is an equitable service in place for those who choose not to take up this option.

Enable people to stay at home as long as possible or be cared for at home

The quantitative response indicates overwhelming support for this key TYC principle. Individual and organisation qualitative comments back up this finding and also emphasised that in the application of this principle we must be mindful of what the individual feels will be best for them.

A strong message emerged that if this key principle is to be effectively applied community based services must be of a high quality and easily accessible. In this regard some concerns were raised about the current

quality of domiciliary care and it was emphasised that increased funding will be required to ensure quality care at home. In their submission, Age NI commented:

“Older people have been very clear in that they want to remain at home for as long as possible and to die at home. The provision of that “little bit of help” enables older people to remain at home for longer and potentially with a reduced package of care.” – Age NI

The British Medical Association cautioned *“that care in the community is not cheap care”* and emphasised the need for highly trained staff to work in community settings.

The impact on families and carers must also be considered in the move towards more care at home:

“Please look after the carers without them this won’t work” – Individual Response

The strength of feeling on carers was such that this has been drawn out as an overarching theme – see Part 4.

In enabling people to stay at home, it was recognised by respondents that there must be clear pathways to hospital care as and when required to support timely access to inpatient care when required.

Who would you like to provide your care/support in your home?

The analysis of responses to this question would seem to demonstrate support for a mixed economy of providers but there is a range of views.

“As the document states the challenge is to provide the right care at the right time in the right place, to achieve this we will need to shape health and social care services to promote the availability of a diverse range of high quality services for people. This will require a strong mixed economy of provision.” – Individual Response

There was a strong feeling that decisions about who should provide services should be based on providers being able to supply an appropriately skilled workforce, who are fully regulated and well paid, valued and supported.

“As long as the care I receive is of a high standard and is client centred I believe anyone can deliver the care and support service if it meets my needs.” – Individual Response

I really don't mind as long as I would be treated with dignity and respect and the person was 'trained for the job'. That might sound obvious but caring involves empathy, someone who can quickly identify changes in a person's condition and articulate concerns to the relevant person."
– Individual Response

This can be contrasted with the view of Staff Side organisations who felt very strongly that health and care services should remain within the statutory sector, and requested that this question be withdrawn. In response to this request, the HSCB replied that one of the principles underpinning TYC was greater diversity of service provision and giving people greater choice in how they access and receive services, we felt it was important to hear people's views on this so that we can make informed decisions about the way forward. We therefore declined to withdraw this question.

Queries and concerns were raised by a small number of respondents about the potential for variable standards of care if a mixed economy of providers was introduced. It was suggested that a mixture of provision may be hard to co-ordinate and may lead to many organisations duplicating services and working independently.

"NISCC would propose that failure to make the registration of the domiciliary care workforce mandatory is a risk to the success of implementing Transforming your Care" – Northern Ireland Social Care Council

The Regulation and Quality Improvement Authority (RQIA) underlined the importance of regulation saying:

"Regulation of the domiciliary care work force is imperative, if the aspiration of Transforming your Care to have the person's home as the hub of care is to be realised." - RQIA

The implications of further regulation in this regard would need further consideration.

Responses from the Voluntary and Community sector were very supportive of moves to introduce a more mixed economy of providers and highlighted the range of innovative health and social care services to which the sector can contribute. Thinking differently about the way we engage with the V&C sector in order to increase choice and diversity of service provision is also discussed in Part 4 of this report. Many of the comments in this regard also touched on the procurement and process of tendering, and this is discussed further in Part 6 of this report.

3.3 HSCB Response

The HSCB is pleased that there is an overwhelming recognition of the need for change and strong support for the principles which underpin TYC. In providing comments on these aspects of the Transforming Your Care and *Vision to Action* documents, respondents often provided further information on what they feel is important in how these principles translate into practice. These have been fed into the analysis of this report.

We believe this is a strong endorsement of the need to progress with the implementation of Transforming Your Care.

Part 4. Overarching themes that emerged during the Consultation Process

4.1 Introduction

Building on the analysis outlined in Part 3, which sets out the strong support for the need for change and the model proposed by Transforming Your Care (TYC) in terms of its vision and principles, a number of respondents (especially those who chose to respond in ‘open’ format rather than utilising the consultation questionnaire), focussed their commentary on the factors which in their view will be critical to achieving the outcomes to which TYC aspires. Some of these were in relation to the Programmes of Care, or specific proposals but many were more general in nature.

This section seeks to draw out some of these overarching themes as they are often consistent across Programmes of Care, to ensure that they are addressed on a more strategic and cross-cutting platform, rather than repeated in each Programme of Care, where some respondents commented that it was difficult to see the overall message or what was proposed in terms of service changes.

Whilst many of these were recognised in the original TYC report, and the *Vision to Action* document, it is clear that greater emphasis could be afforded to them in how changes are explained and implemented.

The five key overarching themes emerging from consultation responses are as follows:

1. The need to ensure that investment is focussed on making change happen, and therefore that alternatives are in place and working effectively before change occurs
2. A greater focus on how carers are supported as a key partner in care provision
3. Workforce as a key enabler to implementation
4. Importance of engaging with the Voluntary and Community sector
5. Need for greater cross governmental / agency working to address health inequalities and be more ‘joined up’

4.2 *Investment in services and ensuring alternatives in place*

Respondents frequently stressed the need to ensure that new service models were adequately funded and established before any withdrawal of current services took place. This was expressed both in terms of the section which set out the need for change, and in relation to specific issues such as the shift of resources to primary care from secondary care and in relation to residential homes. Often groups and individuals sought greater levels of investment in health and social care overall and in specific Programmes of Care.

“More stimulation and activity required but don’t shut down Day Care Centres and provide no alternatives - they do a tremendous job and provide great respite for carers.” - Individual response.

“If care in the community is to be seen as a credible, viable alternative option to care in an acute hospital setting, this will require careful planning, investment, monitoring and review.” - Banbridge District Council.

The standard letters which were focussed on the Causeway Hospital proposals also made reference to this point (1506 respondents):

“If the current system is dismantled before the proposed changes are in place, there will be an overall deterioration in health care.” - Various Individual Responses

Those who commented on this wanted to be reassured that the necessary financial investment for new services, such as Health and Care Centres to support the proposed ‘hub and spoke’ model, would be made and cautioned that there needed to be a clear plan to release funds to follow activity transferring from hospital to community settings.

Others, notably from Staff Side organisations, asserted that TYC would represent a cut in funding for health and social care services.

HSCB Response

We refute the assertion that TYC is about cutting HSC services. It remains that the challenge facing our health and social care system includes rising demand exacerbated by a changing demographic and advances in treatments, and that our current model will become unaffordable in the medium to long term. Transforming Your Care does

not represent a cut in funding for services, but seeks to make decisions about how our model of care can be organised to make best use of the resources and funding available to meet this rising demand. However, it is a financial reality that increased investment will not always be readily available to meet the numerous calls for specific areas to be prioritised as received during this consultation.

Subject to the approval of the Minister to proceed, we reiterate the commitment to having a structured and sensible implementation of the TYC proposals as set out in *Vision to Action*. This includes ensuring that new or different services must, and will, be developed and working well before we step down other parts of the service. In support of this, we would develop measures to track the shift and re-investment of resources into primary and community care settings. The importance of Transitional Funding to enable this to happen has been underlined by the responses to this consultation, as this will enable alternatives to be in place, and support the health and social care system to make the changes in a managed way.

4.3 *Carers*

The issues that affect carers were highlighted more frequently than any other issue in the consultation responses, with the exception of local acute hospital comments. The general public, V&C sector groups and staff organisations all stressed the importance of being better at identifying carers, assessing their needs and putting resources in place to support them.

"The quality, planning and delivery of community care with carers at the core must be fully resources and supported." – Carers Trust

Respondents frequently referred to the planned shift of services from hospital to community settings, and stressed how this depended in some cases on the availability of carers, and how this could be a potential problem given changes in social structures in recent decades.

Promoting greater awareness of the role of carers, greater uptake of Carers' Assessments and a more robust response on the part of HSC to supporting carers was felt to be the core of a better approach to this issue. The provision of appropriate respite that is flexible to meet the different needs of different populations, was felt by most people to be a critical component of providing better support for carers. It was also

viewed as important that carers were engaged effectively when planning and delivering services.

“Carers need to be involved in any planning group that is working on respite/short break models” – Carers NI

HSCB Response

Whilst TYC and *Vision to Action* recognises the importance of carers, and there are specific proposals within some Programmes of Care, we are committed to further enhancing the plans we have drafted for the implementation of TYC as follows, subject to the Minister’s approval to proceed:

- Review the draft Strategic Implementation Plan for TYC to ensure that supporting carers is given sufficient profile and priority in taking forward TYC. We will develop a specific overarching section or project to address carers’ needs, recognising the challenges experienced in the past with developing a regional view of the approach to carers’ needs and respite.
- Actively engage with carers in the design of new care pathways, where appropriate.
- Take every opportunity to promote Carers’ Assessments and encourage service partners to do likewise. Ensure senior management review data on uptake rates for Carers’ Assessments to track progress at promoting wider access to these.
- Ensure that the health and social care needs assessment process incorporates findings from Carers’ Assessments where available so that there is a much better regional understanding of the range of services carers need most, including respite, that is then fed into the service redesign and commissioning processes.

4.4 Workforce as a key enabler to implementation

A significant number of responses mentioned the workforce as a key enabler to success, as recognised in both the original TYC report and *Vision to Action*. There were several strands to the responses in this area:

- the need for effective workforce planning to ensure sufficient skills are where they are needed;
- the need to ensure that appropriate investment in training and skills is in place to support the workforce impacted by changes;
- the need to make appropriate use of the current HSC workforce; and

- the need to understand the impact of any change in staffing numbers.

“On paper the proposals sound very positive and clearly the majority of people would prefer to be cared for in their home over a hospital setting. The success of this, however, will depend on adequate resources in terms of manpower, facilities, equipment, workforce expertise etc.” - Action Cancer.

Some respondents referred to the proposed ‘shift left’ and the move of more care into community settings. Often their comments included a request to ensure that proper workforce planning took place so that the particular skills to provide more specialist clinical care in the community are in place for the time when they will be needed.

“These processes must be supported and underpinned by a coherent workforce strategy, incorporating a workforce development plan that ensures nurses are appropriately prepared to work in different practice settings” -The Royal College of Nursing

In addition, some respondents, particularly from Staff Side organisations, remarked that a lack of workforce planning had caused problems in the past. They felt that this was not an acceptable position and that every effort should be made to ensure that the skills available matched those that were required to provide safe levels of care.

A number of respondents, particularly professional bodies, sought to ensure that the skills of their members were put to appropriate use, whether that meant delivery of specialist care in the community, or participation in the design of care for delivery through ICPs. For example, the Pharmacy Forum highlighted the potential for Pharmacists to take on much more responsibility for care delivery such as vaccination services and minor ailments that would offer more access for patients than is currently available in primary care.

“There is a huge opportunity to make better use of the competencies and skills of pharmacists particularly when there will be a significant shift from provision of services in hospitals to provision of services closer to home; in the community and/or GP surgeries.” - Pharmacy Forum

There were a small number of responses that made reference to the anticipated 3% reduction in HSC workforce over the next 3 to 5 years. Those who responded expressed concern that these would be service critical posts, the disappearance of which would put even greater strain

on those staff left behind. There was a perception on the part of some respondents, in particular Staff Side organisations, that the agenda was one of cost saving rather than any meaningful service redesign.

Comments on workforce were not restricted to those directly employed by the HSC, it was commented that skills and capacity must also be addressed in the V&C sector:

“It is important to note that the community and voluntary groups providing care and support would need to have the appropriate personnel with training/experience. The monitoring of quality and effectiveness would need to be managed well along with the improvement of coordination and communication between the different parties – individuals, statutory and voluntary and community.” -North Belfast Partnership

HSCB Response

In response to the comments from respondents, we would reiterate the commitment made in TYC and in *Vision to Action* that one of the main reasons the way services are delivered needs to change is to ensure the best possible deployment of skills and staff and better networking between sites, to ensure support for the workforce in delivering services to patients and service users.

As with the original review, we did not receive any staff response which argued for the preservation of the existing model of service, and remain convinced that in order to enable this to happen we need to invest in workforce planning and development.

Therefore subject to the Minister’s approval to proceed, we believe the following will be critical during implementation, having regard to the responses received during this consultation:

- Develop detailed planning and modelling around service models and workforce to map the impact of TYC, and ensure that the information is fed into short, medium and long term workforce planning.
- Continue to engage with Staff Side organisations through the establishment of a dedicated consultative forum to facilitate engagement with HSC Trade Union representatives about TYC.
- Continue to engage with professional groups to understand the training needs and implications for professional development as a result of TYC.

- Design how we set up HSCB TYC Programme projects and workstreams to ensure that workforce implications are considered as a core element of their action planning.

4.5 *Importance of engaging with Voluntary and Community sector*

A significant number of respondents mentioned the opportunities that could be gained from engaging with the Voluntary and Community sector in a different way. As one would expect this was expressed by a number of organisations and groups from this sector who responded but it was also mentioned by other individuals and groups.

In addition, a number of stakeholder meetings were held with members of this sector about TYC proposals in general, during which this overarching theme came across repeatedly. This included a cross-government discussion with leaders from the V&C sector, facilitated by the Northern Ireland Confederation for Health and Social Care (NICON).

Some respondents provided examples and evidence of where this has worked well in the past, and argued that a greater spread of innovation and consistent approach would be helpful.

“The use of voluntary and community organisations to support the work of the statutory bodies can ensure a full range of services can be available.” - Action Cancer.

“..quality services can be provided to individuals through a mixed economy approach and AMH strongly advocates that the voluntary and community sector be given the opportunity to play a key role in the delivery of TYC.” - Action Mental Health.

Against the backdrop of TYC proposals in relation to personalisation of care, and promoting diversity of service provision, there were a number of strands or emerging themes from the comments on this area:

- V&C sector often have a unique contribution to make in terms of innovative ideas for service delivery.
- Whilst they perform an important role as service providers in many cases, they also perform a critical role in terms of advocacy, engagement and community cohesion – all of which will be important for successfully transforming health and social care services.

“Having strong advocacy and lobbying groups within communities enables us to hear the needs of our communities and tailor services to meet these needs.”- Community Development and Health Network

- The current procurement rules and practices can, at times, be restrictive to close collaborative working when it comes to service design; equally it is recognised that procurement rules and practices provide necessary protection and good practice.

“In order to retain the unique characteristics of the third sector and achieve greater involvement of the third sector in health and social care, government should undertake a review of its procurement practice which involves the third sector.” – CO3

- The capacity of some V&C organisations to engage with tendering and stakeholder engagement processes (for example as part of ICPs) may be limited, and they recognise that how they organise themselves as a sector to respond will be critical.
- Understanding and building the capacity and capability of the Voluntary and Community sector will be important if more services are to be delivered in community care settings.
- The quality and safety of all services, regardless of who provides them need to be paramount.

HSCB Response

Subject to Minister’s approval to proceed, and in response to the comments from respondents, and as part of the finalisation of the implementation plans to take forward the proposals set out in this document, we propose to address this overarching theme as follows:

- Undertake a specific piece of work to look at procurement of services from the voluntary and community sector across health and social care services, and anticipated needs in future.
- Continue to engage with key V&C umbrella groups, such as NICVA and CO3 to understand how TYC can support capability and capacity building in this sector.

In addition, the DHSSPS will be taking forward work on an inter-departmental basis on involvement of Voluntary and Community groups.

4.6 *Inter-governmental /cross-agency working, and tackling inequalities*

A number of respondents, most commonly those from local government bodies but also Voluntary and Community organisations and individuals, expressed concern that more could be done to ensure closer working with local government or other bodies such as transport services or the housing sector, to improve service access and delivery, and tackle health inequalities. This seemed especially at the fore for those from rural areas, and was mentioned at a number of public meetings.

TYC does not address the "importance of income, environment, employment and housing as key determinants of an individual's health and well-being." - COSTA

Staff Side organisations also raised their concern about inequalities in Northern Ireland and asked for effective inter-governmental and cross-agency working to ensure that each played its role effectively. Local councils stressed their willingness to work alongside HSC, making reference to their new remit for community planning. With their control of facilities such as leisure, environmental health and similar services, they felt that they had a critical role to play in improving the health of their populations.

"Belfast City Council view the integration and sharing of assets (current and future) across the public, community and voluntary and private sectors as critical to meeting local health needs and gaining potential efficiencies for the public purse. It is essential for local government to be directly involved at both a strategic and local level to ensure the desired synergies and efficiencies are achieved". - Belfast City Council

Recognition of "the need for effective cross-departmental working to ensure that the roads infrastructure is there to help ensure effective transport for patients/clients." - Antrim Borough Council

Whilst many of the comments were made at a strategic level, others related to specific Programmes of Care, such as Family and Child Care (including the importance of close working with the education sector), access to Acute Hospital Services (in particular the impact of public transport and road networks), and supporting people to live independently at home (in particular Housing Strategy and Reform). One consistent theme from many of these comments was a desire to see greater levels of joined up thinking across government agencies.

Welfare Reform

Particular reference was made to Welfare Reform by a number of respondents. This related to the need to understand the implications of the Government's Welfare Reform proposals as these will have an impact on the lives of some groups of service users, and therefore could impact on what they need from health and social care services. Some respondents who mentioned this expressed disappointment that the TYC proposals didn't make explicit commitment about how it would link with the Welfare Reform programme and felt this was a weakness in the document.

"LTCANI have concerns regarding the impending impact of welfare reform for many people living with long term conditions and their carers." – Long Term Conditions Alliance NI

HSCB Response

The need for inter-governmental working was recognised in the original TYC Report, with two proposals focussing on the wider role of the NI Executive in decision making which can impact on health outcomes, and joint working projects in areas such as rural isolation and transport. It is appropriate that these matters are policy-led, requiring joined up working at the highest levels.

In terms of the *Vision to Action* proposals and the HSCB implementation of those aspects of TYC for which it has responsibility (subject to Minister's approval to proceed), we believe there will be a need for:

- On-going engagement with the Department for Social Development and other agencies to understand and share plans for Welfare Reform and Housing; and
- Close working with local service providers to continue to engage with local councils during the rollout of local implementation plans.

Part 5. Consultation Responses to the Proposals in TYC: Vision to Action

5.1 Population Health and Wellbeing

5.1.1 What TYC: Vision to Action said

The *Vision to Action* document outlined that there was an overwhelming need to focus on the health and wellbeing of the population and highlighted why strategic and bold action is required.

An increase in obesity and smoking related illnesses, misuse of alcohol and drugs, and the large number of deaths to preventable illnesses each year were the key driving factors for increasing the investment in health and wellbeing. Throughout the document reference is made to the fact that greater investment in preventative care is highly cost effective in the long run.

Across the Programmes of Care outlined in *Vision to Action* examples were given of proposed or existing prevention and early intervention programmes for example *Family Nurse Partnership Programmes* and a number of other strategies were mentioned as these provide the policy framework and direction for work in this area, including “*Fit and Well- Changing lives - a Ten Year Public Health Strategic Framework for Northern Ireland*” and “*Healthy Child- Healthy Future*”.

However there was a recognition that more needs to be done to improve the health and wellbeing of the population especially for those most vulnerable in the system and that we need to make better use of the resources we have.

5.1.2 What people told us

An overwhelming support for a greater focus on prevention and early intervention was evident in the responses received. Many respondents agreed it is crucial that Transforming Your Care (TYC) takes account of and supports investment in and implementation of “Fit and Well”, the public health strategic framework which has recently undergone public consultation. Some commented that TYC could have made a more explicit commitment to addressing health inequalities through its implementation plans.

As “*Fit and Well*” was out for consultation at the same time, no specific questions were asked about population health and wellbeing within TYC, and therefore there is no quantitative data.

A number of themes emerged from the comments on this section:

- The HSC can only make a difference through collaborative community development based approaches working with the whole range of stakeholders, including the Voluntary and Community sector and local councils. It was emphasised that a greater investment in this area of care would be of benefit.
- It was recognised that there are many social determinants of health and many of the comments were in the context of seeking significantly more ‘joined up thinking’ in the design and implementation of public services and health and social care services to address health inequalities.

"If we take action on the social determinants of health we can change patterns of disease while simultaneously reducing health inequalities" - Community Development and Health Network

- Health improvement services need to be more patient centred and easily accessible out of hours and based in local communities.
- It was suggested that there is a need to focus on measuring the outcomes of health improvement initiatives rather than solely meeting targets.
- There was strong support for ensuring all healthcare professionals have access to training in health improvement interventions and expanding roles so that all professional groups can contribute to health and wellbeing. For example, Community Pharmacy NI commented:

"Through community pharmacies key interventions could be delivered to 10% of the Northern Ireland Population every day"- Community Pharmacy NI

- A small number of responses advocated for legislation of the food, drinks and tobacco industries in order to really make an impact on health and wellbeing. There was a strong call for Transforming Your Care to take greater regard of the impact of Welfare Reform and Housing Reform in promoting health and wellbeing.
- A number of respondents emphasised the need to ensure that proposals related to health and wellbeing take account of the rural profile of Northern Ireland and do not disadvantage those populations in rural areas.

- The importance of early intervention and education through schools was emphasised as most health behaviours are established at an early age.

“The Public Health Agency needs to build on key messages that have come from young people. This includes focus on health education in schools and further and higher education establishments in conjunction with the relevant Departments and education providers. Health promotion should also include a range of agencies and not just those directly involved in health and social care provision” - Young People’s Priorities in Health and Social Care (Patient Client Council 2012: 34)

- Many local councils highlighted their role in providing health and wellbeing services and called for greater collaboration with councils and with communities through community planning approaches in addressing health inequalities.

5.1.3 HSCB Response

The consultation on *“Fit and Well-Changing lives - a Ten Year Public Health Strategic Framework for Northern Ireland”* has recently been completed and is due to report soon, and we will support the implementation of this through alignment in our plans and as we move forward with any service changes following this consultation and Ministerial decision.

The need for a strong focus on the prevention of ill health, and promotion of health and wellbeing is one which is recognised by the original TYC report and this is a principle which underpins many of the proposals set out in *Vision to Action* and the draft plans for service changes over the next 3 to 5 years. We agree that this is vital in reducing health inequalities for the citizens of Northern Ireland.

It is also recognised that there are wider social determinants of health inequalities, and health and social care needs to play its part in addressing these, together with other government agencies. In particular the impact of Welfare Reform and housing reform has been raised in this regard and we will seek to engage with the Social Security Agency and Department for Social Development.

5.2 *Delivering services at home and in the community – Integrated Care Partnerships*

5.2.1 *TYC: Vision to Action Key Proposals*

1. There would be initially 17 Integrated Care Partnerships (ICPs) across NI, including all GP surgeries and therefore providing services for all of the population.
2. It is anticipated that much of the **initial focus** of ICPs would be on improving some key aspects of the way services are organised for frail older people, and of services for people with specific long term conditions such as Chronic Obstructive Pulmonary Disease and diabetes. Building on this experience there would be scope for ICPs to evolve and develop into other areas in future. An objective would be to reduce measurably hospital admissions.
3. ICPs would proactively develop and put in place strategies to **identify patients at most risk** of having to go into hospital unexpectedly and put in place plans and actions to prevent this, drawing on the whole range of health and social care disciplines.
4. ICPs would include **strong collaboration** with independent health care providers, and the voluntary and community sectors.
5. **Patient and client representatives** would have a role to play in the oversight of the ICP.
6. ICPs should be clinically led and be based on **multi-disciplinary working**. It is envisaged that GPs would have a key leadership role to play: however, clinical leadership should not be seen as exclusive to General Practitioners and opportunities for leadership development will be inclusive and available to other health and social care professionals. ICPs would be **judged and measured** by how well they improve patient experience and outcomes.

5.2.2 What people told us

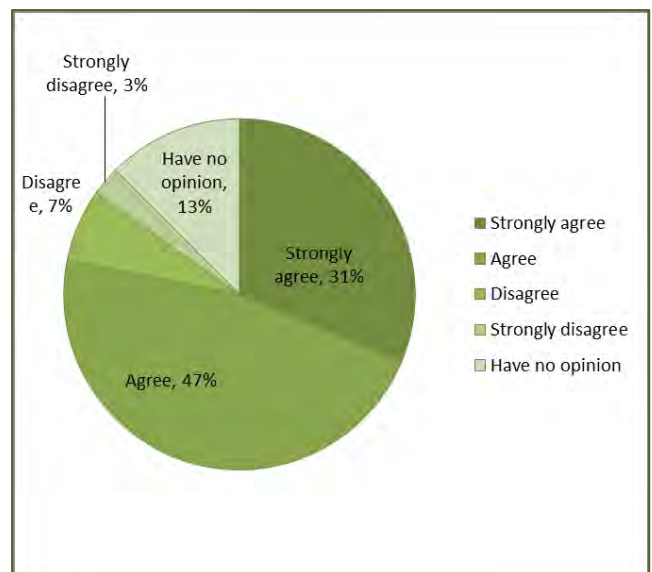
We asked:

Do you agree that Integrated Care Partnerships could make a positive contribution to the delivery of care closer to home rather than in hospitals? If your response is 'disagree' or 'strongly disagree', do you think there are any alternative ways to deliver care closer to home?

Of the 254 questionnaire responses, 224 answered this question. The graph below sets out all the responses we received in percentage terms

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **89% agreed or strongly agreed** that Integrated Care Partnerships could make a positive contribution to the delivery of care closer to home rather than in hospitals
- **11% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

The *Vision to Action* document set out several key areas for ICPs, and some respondents mentioned those specifically. Other respondents made more general remarks or raised issues that were not specifically mentioned in the consultation document.

Clinical and Patient group responses

The Royal College of General Practitioners (RCGP) were broadly supportive of the proposals around ICPs and stressed the importance of ensuring appropriate funding to support the work of these groups. They mentioned their Patients in Partnership Initiative and recommended this model of engagement. The British Medical Association (BMA) was also strongly supportive of the concept, and in addition held the view that GP Out of Hours services should sit within ICPs. In meetings held with

senior medical staff in the hospital sector in Northern Ireland, there was clear support for the proposals around ICPs with attendees expressing a willingness to work collaboratively to develop and deliver care pathways for the targeted patient groups. Some observed that there was a much greater role for primary and community care services in helping patients leave hospital in a more timely fashion and thereby alleviate pressures on the acute system.

“People wanted to see services organised so there was a sense of continuity of relationship with health and social care services; whether in primary, community or hospital care.” The Peoples Priorities for Transforming Your Care 2012 (Patient Client Council).

Some Pharmaceutical bodies (and also Voluntary and Community sector representatives) were keen to work in partnership with ICPs to progress initiatives targeted at the frail elderly and those with long term conditions.

One professional group, the Royal College of Psychiatrists, were less supportive of ICPs, although they strongly endorsed the principle of integrated working across primary, secondary and community care settings, they felt that ICPs had the potential for increased bureaucracy.

The Royal College of Nursing (RCN) expressed concern about the leadership of ICPs and felt that leadership roles should be available to those with the requisite leadership skills rather than being dominated by GPs.

The RCN also highlighted the need for clarity around how the ICP model will fit with existing local commissioning arrangements and, in particular, with the work of the Local Commissioning Groups.

Many respondents felt that whilst the concept of ICPs appeared reasonable, they were unable to give their complete endorsement to the proposals because there was not yet sufficient detail on how the partnerships would work in practice.

Initial focus on frail elderly and those with long term conditions

The majority of respondents who expressed an opinion were supportive of the planned focus of ICPs on frail older people and those with long term conditions. The British Geriatrics Society said the proposals for ICPs were *“a very promising development, and we welcome the focus on frail, older people.” - The British Geriatrics Society*

Focus on patients at risk of emergency admission

Some respondents specifically mentioned the importance of identifying patients at risk and encouraged much closer working between hospital and community teams, including social care professionals to help avoid emergencies.

Collaboration with independent healthcare providers and V&C sector

V&C sector representatives were keen to build strong collaborative working relationships with ICPs. Some respondents, most notably those from Staff Side organisations were critical of the language used in the Consultation document which referred to ‘strong collaboration with independent health care providers’, arguing that this appeared to open the door to privatisation of HSC services.

Macmillan Cancer Support did suggest that some V&C sector bodies would not have the capacity to engage with 17 separate ICPs. This was echoed at the meeting held with the Long Term Conditions Alliance.

Pharmacy and V&C sector representatives highlighted their unique position to support patients, particularly those with long term conditions, but also the frail elderly where they face social isolation and transport issues. Pharmacy providers commented that they routinely pick up and deliver prescriptions for patients who are unable to do so themselves.

Patient and Client representatives and multi-disciplinary working

Many respondents who expressed an opinion were supportive of the concept of ICPs being multi-disciplinary groups that were clinically led. Some non-medical clinical bodies recognised the need for multi-disciplinary work and questioned the role of GPs. For example, the Royal College of Nursing asked that it be made clear that GPs were not the only profession that could fulfil a leadership role in ICPs. Similarly the NI Association of Social Workers questioned the assumption that the new model would be led by a medic. This is already recognised in the proposals in the *Vision to Action* document which says that “opportunities for leadership development will be inclusive and available to other health and social care professionals.”

Other respondents, such as those representing Allied Health Professionals were keen to stress that they had much to contribute to the goals of the proposed partnerships to better support the frail elderly

and those with long term conditions, and highlighted their willingness to do so.

The College of Occupational Therapists stressed the vital role of Occupational Therapy in promoting independent living and asked that ICPs ensured that their profession was able to play a full and active part in their work to target support at the frail elderly and those with long term conditions.

Some organisations, such as Carers NI and the Patient Client Council, emphasised the need for a specific place for service users and carers within the membership of ICPs. In particular it has been suggested that over time service users and carers would take a leadership role in the ICPs.

Other remarks

A number of those who expressed an opinion wished to see greater clarity on the governance arrangements and accountability frameworks that would exist for ICPs, as well as clarity on their role, often remarking that this would be critical in helping them to understand the contribution they will make to delivering care closer to home and better outcomes. In a minority of cases, there appeared to be some confusion over whether the ICPs would be providers or commissioners of services.

Health and Care Centres

Respondents generally wished to see more services provided in the community for the targeted user groups and urged that the infrastructure to support delivery of care in the community was properly developed and resourced. Professional bodies were generally supportive of the proposals to provide more care in the community, with appropriate safeguards to ensure high standards of care.

There were expressions of support for some proposed sites for these facilities. There were occasional expressions of concern that the capital to build new facilities such as health and care centres would need to be protected to ensure that these were built in good time.

Access to Primary Care

Many responses recorded dissatisfaction with the level of access to GP services both in normal hours and out of hours, and looked to ICPs to address this. Some respondents felt that ICPs could add to the

workload of GPs and therefore further undermine access to and delivery of services, and that backfill to protect services was important; others were sceptical about GP willingness to engage with the proposals.

The multiple letters received in regard to services in the Causeway area also made reference to the view that “*GPs are already overworked*”.

Workforce development

A number of respondents, particularly those from professional bodies, remarked on the need to ensure the development of the workforce to support the provision of more services in the community. The need to provide training and support, but also to undertake sufficient advance workforce planning would be very important to ensure that appropriate levels of skills to provide effective community-based care were in place to support a ‘shift left’.

In their response, the British Medical Association (BMA) reflected that there could be an impact on the training of junior doctors by moving services from a hospital to a community setting.

5.2.3 HSCB Response

We have heard strongly that further clarity and understanding of the practicalities involved in the establishment and operation of ICPs is required. That there is support for the proposals and agreement that they will be critical in delivering services closer to home and in the community, which is one of the key objectives set out in the original TYC report.

Subject to approval to proceed by the Minister, in taking forward the proposals, the HSCB will use the detailed comments and responses to inform the plans, and in doing so we will be particularly mindful of:

- The need to clarify areas such as the role of ICPs, their role as a provider, their funding and governance arrangements.
- Provide detail about the establishment of ICPs, the management support they will have and how clinical/social care time will be backfilled to protect service provision.
- How a range of organisations and groups can be better supported to maximise engagement and involvement in the ICP.
- Importance of engaging with stakeholders to understand the skills and resources needed to deliver more community-based services

5.3 Older Peoples' Services

5.3.1 TYC: Vision to Action Key Proposals

1. **Integrated Care Partnerships** would focus on how care is provided to frail older people, particularly by the GP, community nurse and care manager, with much closer working one with the other.
2. A **Falls Prevention Programme** to raise awareness of risk factors and identify those at risk of falls and fractures with the objective of reducing those needing hospital services.
3. Improvements in access times to **cataract surgery and audiology services** to support living at home.
4. **Reablement programmes** in order to promote rehabilitation and independence rather than unnecessary or premature reliance on services, often after an unexpected incident or illness. The HSCB is working closely with HSC Trusts and voluntary and community sector partners to promote and rollout this new service model. As a result evidence suggests it is possible to reduce the number of newly referred older people who need long term domiciliary care service by up to 45%.
5. Promote the **wider use of technology** in the form of telehealth and telecare for remote health monitoring and support with activities of daily living. Providing individuals and families with security and communication options to support people in their own homes. This will help to identify potential problems or the deterioration of a condition much more effectively and allow action to be taken sooner.
6. Further develop and review **intermediate care provision** (including sub-acute and non-acute hospitals), for example when support with rehabilitation is required after an operation or illness. There is a range of such facilities in Northern Ireland. As the new care model develops and alternatives are in place, some of these will expand whilst others will close. It will be for local commissioners to determine the specific changes in individual units to ensure that remaining sites are large enough to provide safe, high-quality care and maintain a safe and efficient level of staffing. Some services will be provided by the statutory sector with some by the independent sector.
7. Increase the opportunity for people to have **self-directed support and individual budgets**; this means that individuals or their carers would be able to have more choice and control about the services they receive.

8. The role played by **carers** is central to supporting the care and wellbeing of older people in the community; consequently, there will be a commitment to improve the quality of life and support for carers through **increased provision of respite and short breaks.**
9. **Implementation of the NI Dementia Strategy**, using in particular the Integrated Care Partnerships to support this process.
10. Enabling individuals to live at home requires a **mixed economy** of service providers to include community and voluntary, private and statutory sectors. Services would be procured to deliver this outcome. This signals a larger role for both the voluntary and private sectors in future. Looking towards this, we will undertake a review to accurately cost such services to ensure value for money and high quality services.
11. Due to improved availability of community-based alternatives, it is expected that demand for our statutory residential homes will further decline. We are proposing therefore **to close at least 50% of our current statutory residential homes over the next 3 to 5 years.** As part of the transitional process towards this, we will consider whether to restrict future admissions in some instances.

5.3.2 What people told us

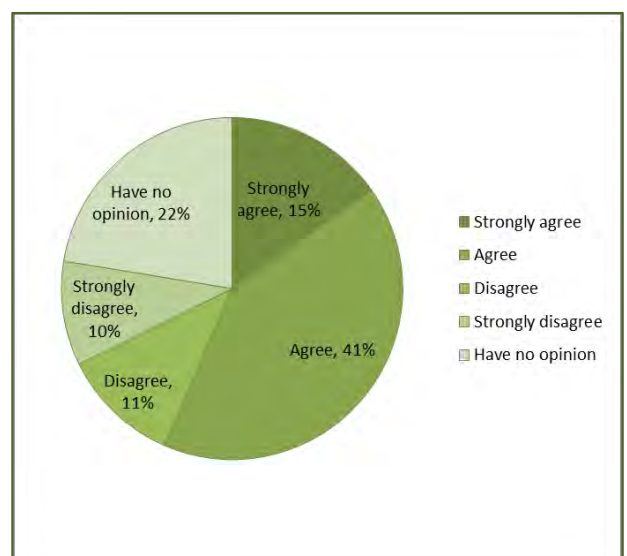
We asked:

Do you agree with the proposals set out in respect of older people's services? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 223 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **73% agreed or strongly agreed with the proposals**
- **27% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

The majority of individuals and groups gave their endorsement to the proposals for older people and welcomed the aspiration to provide care for older people closer to home where possible and appropriate. Respondents did stress there must be choice in the models of care available because people's needs are different. For some older people, care closer to home may not be suitable to meet their needs, considering their health and social circumstances.

"We support the proposals for older people's services underpinned by the concept of home as the hub of care. We support the increased emphasis on promoting independence through the provision of services at or close to home and more support for carers. A great deal of our work is with older people at home and they have confirmed for us their desire to stay at home for as long as possible and to have services fitted around their needs." – Extra Care

Respondents often highlighted the critical role played by carers in supporting older people, and asked that this be borne in mind when designing more community-based models of care. They commented that it will be essential to invest in services such as flexible respite, rapid access to health and social care support and domiciliary packages if we are to help more older people to live independently.

"I agree that older people should be supported in their own home for as long as possible, receiving the care they need and have family around them. However, services in this area must be improved for this service to be successful" – Individual Response

Integrated Care Partnerships

As referenced in the section detailing the responses to ICP proposals, there was broad support for a strong focus on the needs of frail elderly people. There was scepticism among some groups who felt that ICPs will not achieve what they set out to, based on personal experience of services in the past.

Falls prevention, cataract surgery and audiology

Few respondents mentioned these specifically but there were some expressions of support for a focus on improved falls prevention services.

There were no responses that disagreed with these as suitable areas for attention.

Local Government organisations referred to their remit for community planning and in particular their provision of leisure and recreation services. They expressed a keen interest in working in partnership with health and social care services to tailor services for older people to improve mobility, reduce the risk of falls, and offer more opportunities for social interaction.

Reablement / Care at home

A number of responses referred to the proposals around Reablement. Furthermore, the vast majority of those who responded with comments relating to Older People's services remarked on the importance of supporting people to live as independently as possible as long as it is their choice and where it is safe for them to do so. Reablement was not always cited specifically but frequent reference was made to domiciliary support.

Yes- my mother is 94+ and after repair of her broken femur is at home- much more preferable." - Individual Response

A small number of respondents remarked that further evidence is required for the Reablement model.

A significant number of responses highlighted concerns about domiciliary care provision, whether the level of it or the nature of what was provided. Some respondents felt that packages of care were often inflexible and tailored more to providing what was available , rather than meeting the needs of the client. There were some remarks about the short duration of domiciliary care worker visits and how a fifteen minute call was often not sufficient.

In addition, a small number of respondents felt that the Reablement model was important in developing a different way of working with the V&C sector. One respondent commented:

"The reablement proposal is another example for the potential of HSC to stimulate economic growth in the social economy sector while at the same time providing effective care to older people in their homes and community." - Western Investing for Health partnership

Technology

There were few references to technology with regard to older people but of those who did mention it, respondents expressed conditional support for the use of technology to support older people to live more independently, as long as it was remembered that it would not be suitable for all. Some respondents remarked that not all older people would be comfortable using it and therefore would not respond well to it. Some respondents stressed the need to ensure that older people did not end up more isolated socially as a result of the application of technology.

“Older frail people need human contact and interaction as much as a sound building and technology.” – Individual Response

Intermediate Care

There were few references to Intermediate care in the responses received to the proposals for older people other than to note its important role in delivering services.

Self-directed support, individual budgets and enabling a ‘mixed economy’ of providers

There was some qualified support for increasing the opportunity for self-directed support and individual budgets for older people with respondents stressing the need to remember that such initiatives will not suit all situations, whether because of capacity issues or concerns some older people or their carers may have about taking on the role of employer. This indicates that perceptions or past experience with Direct Payments will influence views in this area.

Respondents stressed that there will be a clear need to protect vulnerable people from abuse.

There were very few specific references to the proposal of promoting a mixed economy approach to care provision for older people particularly. V&C sector representatives expressed a keen interest in continuing to provide services for older people and professional groups were complimentary of the input provided by such groups. As mentioned elsewhere, some respondents expressed opposition to increasing private sector provision of services, although their opposition tended to be specific to organisations who would do so for profit.

"We agree with the use of the mixed economy of care, but again the best value/quality ratio must be the driving force here. No group whether statutory, voluntary or independent has a 'right' to deliver care. Commissioners must ensure that the best value/quality teams are used. The evidence for telemedicine and telecare remains scant and large investment in this sort of technology should be avoided until the evidential base for their use is fully developed with this patient group." - North Down Primary Care Partnership

"In the 'shift left' of services towards care in the home or community for the elderly or those with multiple chronicity or specialist needs, a more sophisticated mixed economy of care will be required." - NI Rare Disease Partnership

At some public meetings, representatives of the V&C sector asserted that as alternative providers, not part of the statutory sector, they were working to the same standards of care as statutory providers and that profit was not their motivation.

Carers

The significant proportion of respondents who made comments on the proposals for Older Peoples' services specifically mentioned and strongly supported the need to understand the needs of carers, and to adequately respond to them. This was felt to be so important by so many respondents that this area has been reported separately as an overarching theme in that section of this report.

Implementation of the NI Dementia Strategy

Of respondents who mentioned this subject, all were supportive of the intention to support this strategy. Some expressed disappointment that no funds had previously been made available for it, and their hope that TYC would remedy this.

Closure of 50% of current statutory residential facilities

This proposal generated much discussion and comment from respondents both at public meetings and via written responses. Whilst some respondents recognised that remaining independent at home is often preferable, or that good alternatives exist (including non-statutory residential care or supported living accommodation), they were also keen to maximise choice. The majority of comments from those who

disagreed with the proposals for older people were related to Statutory Residential Homes.

Some respondents on this proposal were anxious that if some statutory residential facilities closed, there would be a gap in provision of service for people for whom support was currently provided in such settings. It was clear that the public wished to have detail on what alternative support services would exist in each locality to address the needs that are currently being met by statutory residential care, and to be reassured that these would be as good if not better than the current arrangements.

“There is concern over closure of some residential homes but an understanding that places of care could be run differently with more innovativeness. The need to acknowledge the specific social needs of older people and their family unit.” - South Belfast Partnership Board

“If residential homes are closed, they should be closed because they are no longer needed as alternatives are in place, rather than by a Trust making a decision without that adequate community support.” - Dr Brian Dunn, GP, NI Conservatives Health Spokesman

Also some asked for consideration of issues of social isolation and the role that statutory residential homes currently play in providing social interaction for people by virtue of sharing accommodation. Respondents wanted to be reassured that this issue would be given priority status in any planning to reduce residential provision so that people who received an alternative form of care to statutory residential care in future would still have the opportunity to spend time with other people.

Some concerns were noted around the process of moving current residents to different settings if their current home closed, and how this process would be managed to minimise distress to residents and families. Reminders were provided that for residents, this is their home.

“Many older people cannot manage at home but do not require intensive nursing support therefore there is a need for Residential care until Trusts or housing associations can provide supported living alternatives.” - Individual Response.

Some attendees at public meetings referred to previous home closures and wanted to be assured that any changes would be carried out in a way that was sensitive to the needs and wishes of residents and carers.

“Important to manage the re-provision of Rathmoyle Residential Home in a manner that meets the needs of and enjoys the confidence of the service users, carers and the wider community.”- SDLP, Moyle District Council

The Commissioner for Older People asked that a framework be put in place to ensure a sensitive and pragmatic approach to any changes. Age NI, whilst not opposed to the proposals, did ask that any changes are done in consultation with older people and carers and that any funding released goes into community and primary care services, and also proposed an agreed framework is put in place for doing so.

Some V&C responses also cited the need to carefully consider relocation of residents, as moves can be difficult for older people, particularly those with memory impairment. The Alzheimer’s Society stressed, that any reduction in the numbers of care homes must be contingent on a significant investment in the quality and availability of home care.

A small number of responses expressed concern about the impact on staff currently working in statutory residential facilities that could face closure. Staff Side organisations stated their opposition to the proposals to close statutory facilities, asserting their perception that the proposals were a privatisation and cost-cutting exercise.

They raised concerns that staff in these settings would suffer a detriment to their terms and conditions of employment if they worked in the independent sector and that staff are anxious about the impact of the proposals to close some residential facilities.

Some respondents questioned why it was only the statutory sector that was to be reduced and no mention was made of similar reductions in the independent sector. This highlights the need to clarify exactly what is intended in the proposals – that it relates only to statutory residential facilities for older people, not EMI (Elderly Mentally Infirm) facilities, or those for people with Mental Health or Learning Disability-specific placements. It would also be helpful to clarify that some of the current facilities may continue to provide respite care.

Reference to current examples of innovative new developments, such as Cedar Court in Kilkeel were made and it was suggested that it may help to provide examples of what is now possible, and thereby reassure the public that a different model of care to the traditional statutory residential care service can work very well for some people.

We received some letters from a small number of support organisations for residential facilities such as Friends of Lisgarel, Friends of the Roddens and the Portballintrae Residents Association which stressed that there would always be people for whom independent living was not an option, and there was no alternative to residential care. It was said that it would be important for the HSC to demonstrate that for people who really need residential care support, this will still be available, albeit this may be in a different facility in some instances. It is also important to reflect the fact that the needs of older people change as they get older, and that some of the people currently in residential care would eventually have had to move to an alternative setting because the time would come when they would need more intensive nursing care.

Other remarks

“Older people are not a heterogeneous group” - AGE North Down and Ards, stressing that the needs of the older population need to be properly identified and understood.

Some respondents mentioned issues around fuel poverty and the need to ensure that people living independently were not put at risk by living in a cold environment.

A small number of respondents stressed the need to ensure rapid access to and provision of equipment and adaptations to help people remain in their own homes, or return to them after a period of ill health.

5.3.3 HSCB Response

There is broad support for the proposals made in *Vision to Action* for Older People’s services, in particular making the home the hub of care for older people which means promoting independent living at home, and care closer to home, where it is safe and appropriate to do so. This includes addressing people’s social needs to avoid isolation within their communities, and the continued development of intermediate care and respite services to support rehabilitation.

With regard to the proposals for statutory residential homes, we recognise and acknowledge the anxiety and concern expressed by some respondents. We reiterate the commitment to providing greater choice for older people, and that it is extremely important that any transition ensures alternatives are in place and working well, and that

implementation would be in a planned and managed manner with residents, families and local communities involved in local consultation processes. We also believe that statutory residential care is not always able to provide the best facilities for older people, and better alternatives currently exist and will continue to be developed, such as supported living accommodation. Through this consultation we have not received any compelling evidence that investment in these alternatives, which can be enabled through the closure of some statutory residential homes for older people, is not the most appropriate way forward.

Therefore, subject to the approval of the Minister to proceed, we will move to provide details about what changes to residential care provision would mean, and how the public and stakeholders can be involved in any changes that affect them. All such changes would be subject to local consultation.

In moving forward with the plans for Older People's services, we are committed to the following, which came through particularly strongly in the responses:

- The need to provide more information on the alternative models of care that will be available, with assurances for the public that the timescales will be carefully planned to ensure that there will not be a gap in provision of essential services.
- Seek to develop a framework for transition for those currently in residential care which may be impacted.
- Changes should also set out what the impact for staff working in any facilities that close will be and provide the necessary details about employment protection.
- Consider issues such as social isolation when developing implementation plans.
- When planning services for older people, maximise effective engagement with and input from other agencies with responsibilities for; housing, recreation and leisure, transport, V&C sector, local enterprise organisations, where appropriate.
- Any future plans would need to be developed with openness and transparency, in consultation with Staff Side organisations, demonstrating that the employer discharges their full duty of care to staff under the law.

5.4 Long Term Conditions

5.4.1 TYC: Vision to Action Key Proposals

1. To develop **new LTC 'Care Pathways'** – this means that all those responsible for or involved in providing you with health care services at the moment would develop simpler ways for you to access services, often through your GP or specialist nurse at home. At times this may mean that you may be admitted directly to hospital if you need to be, rather than having to go through A&E.
2. Using the latest clinical evidence we would develop '**risk profiling**' which would help those providing care to target specific support for those most at risk of an acute episode who may need a hospital admission to help to prevent them needing to go to hospital at all.
3. You would be supported and receive education on how to **manage your condition yourself** so that you would more easily identify when you are getting worse or your medication may need to change.
4. **Appropriate follow-up and regular review** of your condition by your GP or practice nurse. This would mean a change in the way hospital specialists work and mean that you get more follow up care.
5. Your pharmacist would play a key role in helping you understand your condition and how to **manage your medication** effectively.
6. Investment in new technology called '**telemonitoring**' where this is appropriate to your situation. This means that you may have new technology in your own home to monitor and test your condition, enabling your clinicians to receive information about your condition in a realtime or regular basis. This can mean that issues are quickly identified and dealt with.
7. Putting the range of initiatives set out in the plans in place would mean there are **fewer emergency visits to hospital** and a reduction in the amount of time you need to spend in hospital when you have an acute episode.

5.4.2 What people told us

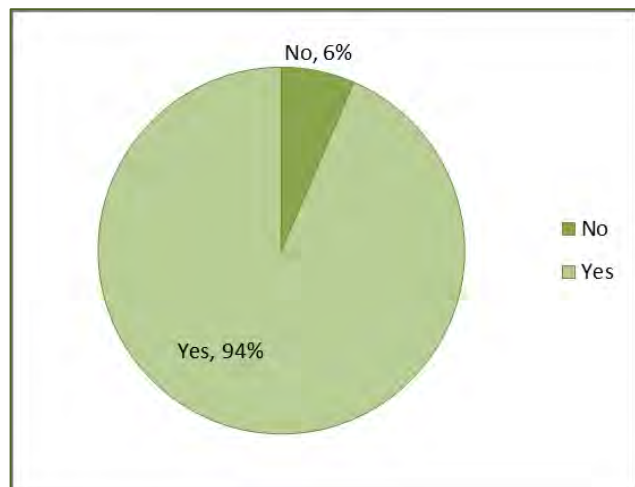
We asked two questions in relation to the proposals for Long Terms Conditions

1. *Would it be helpful to make more information and education available to help those with LTCs monitor and manage their condition?*

Of the 254 questionnaire responses, 232 answered this question. The graph below sets out all the responses we received in percentage terms

The statistical analysis of the responses to this question show that

- **94%** felt it would be helpful to make more information and education available to those with LTC's
- **6%** felt it would not be helpful

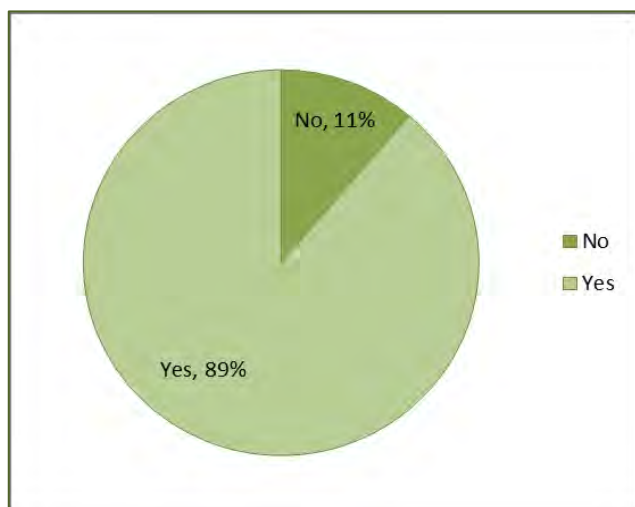


2. *Would it be helpful to enable those with LTCs to make more use of technology in their home to identify problems earlier and reduce need for avoidable visits to hospital or the doctor?*

Of the 254 questionnaire responses, 223 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that

- **89%** felt it would be helpful to make more use of technology in their home
- **11%** felt it would not be helpful



In addition, a number of themes can be drawn out from the comments we received about these proposals:

The majority of those who responded expressed support for the proposals to provide more information and education to improve self-management, and to make greater use of technology in the home to identify problems earlier and reduce the need for hospital visits.

Professional groups such as hospital doctors, General Practitioners and V&C sector groups that represent particular long term conditions all welcomed the increasing focus on improving self-management, home-based care and changing the pattern of care to a more community-based one.

There were a number of specific areas featured in the Consultation Document as part of the proposals around Long Term Conditions. Where responses were made to those the key messages are summarised below.

Pathways, risk profiling, self-management and appropriate follow up and reviews

Some respondents referenced Service Frameworks as a useful tool in setting out appropriate pathways, and in the case of Diabetes, a specific service framework was requested, with Diabetes UK arguing that this would improve the health and wellbeing of this patient group.

There were few references to risk profiling although a small number mentioned this directly, including Diabetes UK, encouraging health care services to develop a better understanding of the 'at risk' population in Northern Ireland.

Of respondents who expressed an opinion, the majority were very supportive of the proposal to provide more information to patients to help them manage their conditions more effectively, including when to make use of each type of care service.

Many respondents felt that patients would prefer to have their care delivered closer to home although it was often stressed that for some, hospital care would be the most appropriate and that it was important that any pathways guaranteed swift access to specialist opinion and treatment where required.

Responses from Pharmacy and Pharmaceutical bodies all stressed the significant contribution they had to make to improve the health and wellbeing of patients with long term conditions. Professional bodies highlighted the potential for pharmacists to provide support and information to patients and carers to ensure that medicines were used more effectively, and with appropriate protocols, to play a part in supporting patients to manage their conditions in the community. Responses from this group welcomed proposals to focus on pathway design, self-management and appropriate follow up and reviews.

The British Geriatrics Society remarked that it is important to bear in mind that very few older people have only one long term condition; the majority have two or more, and that this means pathway design has to take account of such complex co-morbidities.

Technology

A number of respondents, including those who spoke at public meetings, highlighted the problems of internet access and broadband coverage for more rural areas. They felt that this could compromise proposals to have more remote monitoring of patients with long term conditions; however they accepted that where this was possible, it could be of benefit.

Some respondents mentioned the need to consider the whole circumstances of the person when trying to decide whether remote monitoring was an option. There could be issues of capacity, where lack of face to face contact with a health care professional could lead to increased levels of anxiety. For other patients, the contact with a health care professional calling at their home could be one of very few social interactions they had, and taking that away could lead to the person feeling more isolated.

The implementation of the proposals in relation to long term conditions will need to carefully consider how these will impact on the relationships between the various stakeholders, particularly the patient. Whilst the word 'remote' could raise concerns that patients will have much less contact with health care professionals than is currently the case, it would be important to stress what the style of that contact is intended to be in future, and that it would be a much more pro-active relationship with key clinical staff to avoid stressful emergencies and build a partnership between clinicians and the patient. The faster access to specialist investigations, opinion and advice brought by the use of technology

should be considered an important element of building this new style relationship.

Other comments

The V&C sector responses generally expressed a keen interest in being involved in the planning, design and delivery of specialist interventions in their area of expertise. They noted that they have long experience of partnership working with HSC at local level and that there was considerable expertise there to be drawn upon. They wished to provide more specialist input but as referenced elsewhere, they sought help and support in dealing with the rigours of procurement, which were particularly difficult for small organisations with little management infrastructure.

Some responses were received from V&C sector representatives of specialist interest groups which highlighted that there are rarer conditions such as Muscular Dystrophy, Multiple Sclerosis, etc. that are long term conditions which are not specifically mentioned in the proposals and requests that these conditions should be included in the planning of services.

Some respondents asserted that cancer should increasingly be seen as a long term condition as survival rates continue to improve and people are living with cancer for much longer than in the past.

5.4.3 HSCB Response

Overall there was strong support for the need to focus on the care pathways for long term conditions, and support patients to be more self-managing, where this is appropriate to do so. This includes the increased use of technology, where it is appropriate.

Having considered the responses to the consultation in this area and subject to approval of the Minister to proceed, as we develop plans for the implementation of proposals it is recognised that we need to be particularly mindful of:

- The need to provide information based on practical examples for the public, particularly those affected by long term conditions, on how the care they receive could be different under the proposals, how this would impact on their quality of life and the type of contact they have with clinical staff and health services.
- Develop an accurate understanding of levels of internet access/ broadband coverage to allow an assessment of where remote

monitoring is an option, as a key enabler to the investment in 'telemonitoring'.

- Ensure that roll out of remote monitoring or other technology-based supports also takes account of factors such as social isolation.

5.5 *Palliative and End of Life Care*

5.5.1 *TYC: Vision to Action Key Proposals*

1. To greatly increase the number of people who are **supported to die in their preferred location**, where they have expressed a preference.
2. **More 24 hour community support** for people in the last year of life, in accordance with their assessed needs.
3. Implementation of the **End of Life Care Operational System** (EOLCOS). This is a system to identify people who may be in the last year of life .It allows for the beginning of a discussion which will support people to express their needs and preferences of how and where they would wish to die.
4. Increased access to **specialist palliative support** out of hours, including specialist 'in-reach' into nursing homes and people's homes when they need it.
5. Working more closely with the **voluntary and community** sector in the provision of palliative care.
6. Better links and **integrated working** between specialist and generalist services, especially through the Integrated Care Partnerships.
7. Increase the **education and training** (and therefore the number) of staff confident and competent in the core principles of palliative and end of life care in all sectors.

5.5.2 *What people told us*

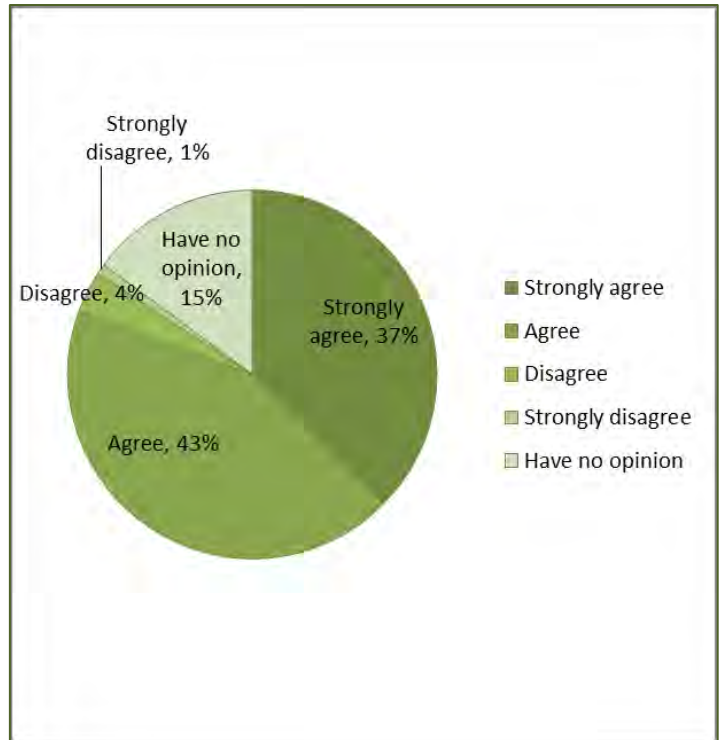
We asked:

Do you agree that the proposals set out in respect of palliative and end of life care would support you to be cared for in a place of your choice? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 222 answered this question. The graph overleaf sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **95%** agreed or strongly agreed that the proposals would support them to be cared for in a place of their choice
- **5%** disagreed or strongly disagreed



In addition, a number of themes can be drawn out from the comments we received about these proposals:

There was strong endorsement for implementation of the palliative care and end of life proposals laid out in the consultation document. It was also recognised that implementation needs to be planned for and thought through to address challenges ahead.

“We greatly welcome proposals set out in relation to palliative and end of life care. We agree that better links and integrated working between specialist & general services, especially utilising the structure of the ICP’s are required” North Belfast Partnership

A collaborative response from Marie Curie Cancer Care, Northern Ireland Hospice, Macmillan Cancer Support, Southern Area Hospice Services and Foyle Hospice commented:

“Whilst we fully support the policy direction of Transforming Your Care, there is much work to be done to translate those elements which are still at an aspirational level into practical results.” – Collaborative response from Marie Curie Cancer Care, Northern Ireland Hospice, Macmillan Cancer Support, Southern Area Hospice Services and Foyle Hospice

There is a recognition by respondents of the need for close working with, and further investment in the implementation of *“Living Matters, Dying*

Matters”, the Palliative and End of Life Care Strategy for Adults in Northern Ireland.

Some challenges were outlined by professional groups in supporting people to die in their preferred location, including;

- the need for greater clarity on roles and accountabilities;
- queries about how progress will be monitored; and
- the need for training and awareness raising amongst staff and the public.

Respondents identified implementation of the End of Life Care Operational System (ELCOS) as key to improving palliative care and advocated for an awareness programme to support its use. One comment was:

“We strongly support this model and the potential it holds to bring clarity to key questions around EOL care provision, when it begins, roles and responsibilities etc. not only for care providers but for patients their families, carers etc.” – Collaborative response from Marie Curie Cancer Care, Northern Ireland Hospice, Macmillan Cancer Support, Southern Area Hospice Services and Foyle Hospice

Some respondents suggested that the most effective model is one where specialist palliative care teams are centred around and support GP practices to allow support from specialists to local teams who know the family best.

Respondents from the V&C sector highlighted a need for funding of bereavement care and support services for young people, which in turn will improve mental health for future generations.

Advanced care planning and conversations around death and dying have particular implications where capacity to make decisions or to express wishes diminishes and this must be taken account of. In this context, there were some concerns raised that there is a lack of reference to how people will have choice and control over planning of services for end of life care. It was emphasised that families must be involved in decision making.

Palliative and end of life care for children and young people was highlighted as an area in particular need of focus, and children and young people must be involved in their own end of life care planning.

The Voluntary and Community sector has a big role to play but some caution was expressed to ensure that staff from this sector are effectively supported and trained.

Some responses highlighted that there will always be occasions when inpatient end of life care is required and we must ensure there is enough inpatient and hospice capacity.

5.5.3 HSCB Response

Of those that expressed an opinion about Palliative and End of Life care, there was strong agreement with the proposals put forward. Many of the qualitative comments underlined the need for supporting people to die in their preferred location, with increased access to specialist care. It was recognised that this needs to be enabled by appropriate training and skills, more close working with the V&C sector, and a clear focus on practical results. It is recognised that an Implementation Board is already in place for *Living Matters: Dying Matters*, and their sub-groups and workstreams will take the lead in this area.

The responses received in this area will be used to inform this and in developing the implementation plan, subject to Ministerial approval to proceed, we will be particularly mindful to the following:

- The need to prioritise development of a cross sector programme of development and education for palliative care, underpinned by an assessment of current skills and capacity. This will support delivery of proposals 2, 4, 6 and 7.
- Specifically in support of proposal 5, progress the development of an explicit procurement process to ensure capacity and capability building, and effective engagement with the voluntary and community sector in provision of palliative care services.
- The need to engage with forthcoming reviews of palliative care for children, and ensure that the outworkings of the review are built into TYC plans in a timely manner.

5.6 *Mental Health*

5.6.1 *TYC: Vision to Action Key Proposals*

1. Be **more joined up** in how we provide services, in particular, how mental health services work with GPs (and other primary care providers) and hospitals – this is critical to getting better at earlier intervention.
2. In line with the Bamford Review recommendations, **reduce the number of people in institutional care and inpatient beds** by existing residents moving to live in the community through intensive home support, alternative supported living arrangements based in the community, and individual budgets. This will take full account of the complex family dynamics in this area.
It is our intention to continue with the Northern Ireland Executive's resettlement programme. At the point of writing, this means that the remaining 116 people from the original targeted group identified in 2007 would move to alternative community based living arrangements, by March 2015. We would also work towards resettling those people who have become long stay residents since 2007, due to delay in their discharge for longer than a year.
3. **Develop 6 in-patient acute mental health units** for those aged 18+. There would be one site in the Northern, Southern, South Eastern and Belfast areas, with two in the Western area. In order to reduce stigma and ensure there is good access to acute care, it is necessary to locate mental health hospitals close to acute hospital provision, recognising that this may not be possible in all circumstances. These principles would imply that the second location in the Western LCG area would be in the proximity of the new South West Acute Hospital rather than Omagh as previously planned and this consultation seeks views on that issue of principle.
4. **Enhancing the support for carers**, to ensure they have access to services in their community which enhance their quality of life.
5. **Promote the uptake of self-directed support and other programmes** which would mean that people have more choice and control over the type of care they receive.

5.6.2 What people told us

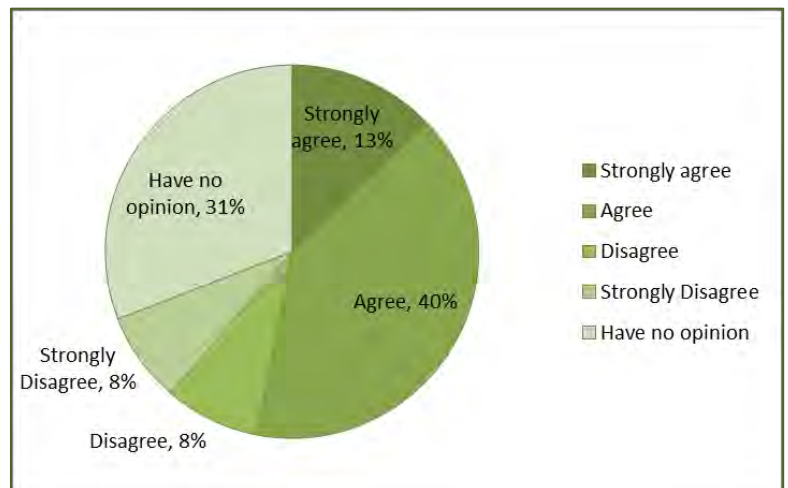
We asked:

Do you agree with the proposals set out in respect of mental health services? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 217 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **77% agreed or strongly agreed with the proposals**
- **23% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

There was general support amongst respondents for the continued implementation of Bamford recommendations. Some respondents expressed a sense of disappointment and frustration that putting this into action has been a slow process but were hopeful that Transforming Your Care would add new drive and impetus to the process.

"We welcome the continued emphasis on the reorientation of provision towards community mental health provision."- NIAMH

"needs to build on and pace up the implementation of Bamford recommendations, work really closely with carers, service users and the third sector and demonstrate leadership which genuinely embraces the ethos of social innovation."- CAUSE

Acute Mental Health

An area of debate during the consultation process and in the responses received has been in relation to the placement of a second mental health inpatient unit in the Western LCG Area. Support for placing this unit in Omagh on the site of the new Omagh Enhanced Local Hospital was expressed by the Western Health and Social Care Trust, Omagh District Council and some members of the local community. A very small number of those disagreeing with the proposal via the questionnaire referred to this matter. Support for retention of inpatient mental health services at the Tyrone and Fermanagh Hospital were also expressed at the public meeting held in Omagh.

Reasons given included:

- The retention of expertise and experienced staff working in Omagh.
- The historical role of mental health provision in the area.
- The potential negative economic impact to the local community if the mental health unit was relocated.
- The infrastructure of the new enhanced hospital has commenced.
- The Western Health and Social Care Trust also suggests that the placement of the acute mental health inpatient unit in Enniskillen may impact on the provision of old age mental health care.

Conversely medical opinion has been strongly in favour of co-locating the new mental health inpatient unit with the South West Acute Hospital in Enniskillen. The Royal College of Psychiatrists firmly endorsed the co-location of acute mental health units alongside an acute hospital. Building on their stance expressed in the 1998 document "*Not Just Bricks and Mortar*" stating that:

"15 years on, the case for being on an acute site is even more compelling. Those admitted are significantly more disturbed than in the past and access to a cardiac resuscitation team is seen as important....[A] closer working relationship between psychiatrists and other doctors is clearly a good thing, and is further argument for the acute treatment of the most severely mentally ill to be on the same modern sites, as that for the most severely physically ill." – The Royal College of Psychiatrists

The British Medical Association state that they

"concur with the view that mental health hospitals should be located close to acute hospital provision."- The British Medical Association

Others concurred with the need to ensure access to general hospital services but further suggested that in agreeing the location of units, further criteria should also be used, including travel distance and time for both patients and family.

The transition of Mental Health services out of hospitals and into the community was greeted with approval from respondents, however there were a small number of respondents concerned that there would not be enough inpatient beds in the planned 6 mental health units.

The importance of access to a psychiatry liaison service for all general hospital patients was highlighted. There is significant correlation between physical and mental problems and it is important they are treated in an integrated way.

It was expressed by some (most notably by the NI Association for Mental Health) that Emergency Departments are often unsuitable environments for mentally ill individuals and as a result should be avoided where possible. Direct admission to wards, improved working across primary and secondary care and better access to care in the community were put forward as ways to accomplish this goal.

Resettlement

The resettlement of mental health patients and allowing those with mental health issues to remain at home for as long as possible was supported by consultation respondents, with The Law Centre stating that it:

“welcomes the proposal to reduce the number of people in long term institutional care in line with the Bamford recommendations.”- The Law Centre.

Appropriate capacity and capability in the community to care for those with serious mental health concerns, including alternative accommodation must be in place for this to happen. It is recognised that resettlement for those with complex and challenging behaviours will need to take account of their particular needs. The focus must be on enhancing the service user experience rather than just replication in a different setting.

Support for carers in the form of respite was mentioned as vital to enable the resettlement of long stay mental health patients into the community. For example, CAUSE stated that:

“No-one wants to be in hospital where this can be prevented. This would also be the view of carers who actively support loved ones who have experienced serious mental illness.”- CAUSE

Primary Mental Health

While the issue of the placement of the Western LCG Area’s second mental health inpatient unit was the most emotive issue it was noted in a number of responses that the vast majority of mental health is now already based in the community and the home. Greater access to Cognitive Behavioural Therapy (CBT) and other primary and preventative care was expressed as a priority.

Some respondents felt that health and social care staff would benefit from greater awareness of mental health issues. This was emphasised in relation to primary care with special focus placed on GPs as gatekeepers to further care. Questions were raised asking for clarity on the role for ICPs in relation to mental health. The possibility of an expanded role for Community Psychiatric Nurses was suggested and for pharmacists in relation to medications management.

Stigma was highlighted as remaining a key issue attached to mental health. Co-location of inpatient mental health services with acute hospital services was seen by most as a means of reducing stigma but more would be needed. Raising public awareness of mental health concerns was advanced as a means to achieve this goal. Inter-departmental and joint agency work tasked at reducing stigma at an early age in schools was highlighted as important for achieving this aim, and educating the public on mental health.

There was support from a number of respondents for the role of the V&C sector in delivering services. There was also support for greater involvement from service users and the V&C sector in the shaping of Mental Health services. The role of service users shaping services in Belfast Health and Social Care Trust was proposed as a case of best practice that should be extended.

The central goal of *Transforming Your Care* for people with mental health problems to live at home will rely on the commitment and hard work of carers. Support for carers has already been highlighted as a central theme that has emerged from the consultation process across the whole spectrum of health and social care, and this was further endorsed by respondents in this area.

Pathways across Primary and Secondary Mental Health

Respondents noted the opportunity presented by TYC to improve pathways in health for people living with mental illness. Simplicity and clarity in managing the health and care system was highlighted as an area for improvement. This was true in moving from primary to secondary care, but also a need for more rehabilitation and intermediate facilities to aid the transition from secondary to primary care.

5.6.3 *HSCB Response*

Of those that expressed an opinion in regard to the proposals for Mental Health services, there was broad support for the direction of travel and the proposals as a way of achieving the aims set out. In particular the need to progress with Bamford was supported, and in alignment with the discussion and proposals in the original TYC report, the need to accelerate and invest in doing so. A small number of responses contained specific suggestions on the way forward, and, subject to the Minister's approval to proceed, we will be mindful of these in developing implementation plans, in particular the need to ensure that joined up community services are in place to support this aim.

With regards to the location of acute mental health inpatient units, the response to the consultation, in particular from clinical opinion, would indicate that the principle of being close to an acute hospital is appropriate in order to reduce stigma and be close to other acute services. In relation to the location of the second acute mental health inpatient unit in the Western area the application of this principle in light of this consultation would benefit from further consideration. Therefore we would propose that a further options appraisal is undertaken in relation to this matter.

5.7 *Learning Disability*

5.7.1 *TYC: Vision to Action Key Proposals*

1. In line with the Bamford Review recommendations, **reduce the number of people in long stay institutional care** by existing residents moving to community based options and reducing new admissions through the continued development of self-directed support, supported living arrangements and individual budgets. This will take full account of the complex family dynamics in this area. It is our intention to continue with the Northern Ireland Executive's resettlement programme. At the point of writing, this means that the remaining 175 people from the original targeted group identified in 2007 would move to alternative community based living arrangements, by March 2015. We would also work towards resettling those people who have become long stay residents since 2007, due to delay in their discharge for longer than a year.
2. **Improve access to respite** and provide a wider range of non-facility based respite for both service users and carers. This will reduce the number of people being admitted to acute beds.
3. Increase the number of people with **self-directed support and individual budgets**; this means that people have more choice about what services they receive.
4. Continue to develop creative and **age-appropriate day opportunities** to promote independence and choice, such as access to employment, leisure and educational activities. This will include more opportunities being provided in partnership with other sectors (including voluntary & community, education and employers). Our statutory facilities may be re-configured as a result.
5. Enhance the **involvement of carers** in care planning and service planning to bring their experience to bear on these functions.
6. Be **more joined up** in how we provide services for people with learning disability so that they have a seamless service when accessing specialist services and health screening.

5.7.2 What people told us

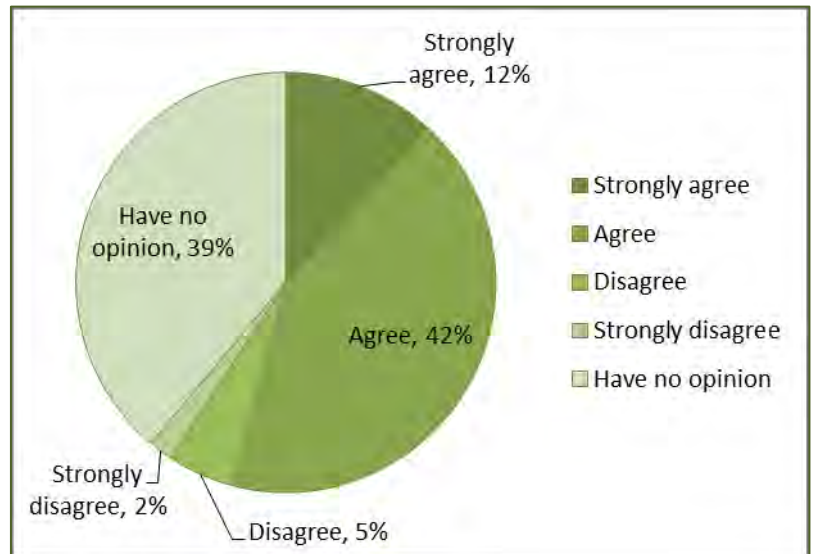
We asked:

Do you agree with the proposals set out in respect of learning disability services? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 212 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **88% agreed or strongly agreed with the proposals**
- **12% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

There was general support amongst respondents for the continued implementation of Bamford recommendations. Respondents expressed a sense of disappointment and frustration that putting Bamford proposals into action has been a slow process but were hopeful that Transforming Your Care would bring added impetus. The values of the Bamford report are reaffirmed as the blueprint for the transformation of health and social care for those with learning disabilities, but the process moving forward must not be limited to Bamford.

In addition to agreeing with the proposals, some respondents sought further investment in Learning Disability services, and suggested further areas they would like to see addressed through the implementation plans for TYC.

Resettlement

An issue that has been seen as controversial has been that of the resettlement of long stay learning disability patients into the community, as outlined in Bamford. The majority of responses have been supportive of the proposal. Alongside this agreement some pleas were raised around the timescale of resettling patients and whether there is adequate capacity in the community to care for these patients. Frustration amongst respondents is noted concerning the slow pace of the resettlement process thus far. Also highlighted by some respondents is that those patients still remaining in long stay institutions will be the most difficult to resettle and will require a higher level of support to live in their own homes.

Older People with Learning Disability

There is a need for greater recognition on the growing numbers of people with learning disabilities reaching old age, according to some respondents. This was expressed by the NI Local Government Association as follows:

“This group have very individual needs and with greater life expectancy, there is a requirement to agree - with them, their families and / or carers - arrangements for their lifelong care.” -NILGA

This has been thanks to advances in health care and is to be celebrated however as a result there were clear suggestions that the particular needs of older people with learning disabilities need to be recognised. Age appropriate services for older age people with learning disability will need to be developed to reflect this growing demographic. The carers for these older people with learning disabilities are in most cases elderly themselves. The need for these older carers to have confidence that those they care for will be safeguarded and cared for into the future was expressed. Supported living schemes have a role in addressing this growing need, and more work needs to be done to provide this service.

Age Appropriate Services

The need for flexible and “age appropriate” services was addressed by individuals and by the Patient Client Council. The period where people with learning disabilities move from childhood into adult services was indicated as an area that needed particular attention. The role of day services for adults with learning disabilities was indicated as particularly important.

Access to HSC Services

Some respondents expressed that there was currently a difficulty for people with learning disabilities to access other services. Access to mental health services for people with learning disabilities was indicated by the Royal College of Psychiatrists as a particular area where more work could be done; while some people with learning disabilities access mainstream mental health services, many still do not. Greater joint working between learning disability services and other areas should be promoted. The need for greater access to Dentistry was also highlighted.

Staff

There were calls for staff training relating to learning disabilities for practitioners to better facilitate communication and help involve people with learning disability in decisions being made about their lives. Having a specialist learning disability nurse in each hospital was proposed in the response of Barnardo's Disabled Children and Young People's Participation Project.

Carers Needs

The central goal of Transforming Your Care for people with learning disabilities to live at home will rely on the commitment and hard work of carers. Support for carers has already been highlighted as a central theme that has emerged from the consultation process across the whole spectrum of health and social care. Specifically for carers of people with learning disabilities a lack of access to information is a difficulty, as noted by the Patient Client Council and Positive Futures.

Community

Greater independence for those with learning disabilities was praised:

NICVA is encouraged that fundamental to TYC there is a commitment to delivering the best outcomes for people with learning disabilities by increasing their independence and choice" - NICVA

Respondents proposed this will require inter-agency and inter-departmental co-operation. Support for opportunities in the community for education and employment for people with learning disabilities was voiced with particular support for the social firm model to provide employment opportunities for the learning disabled. This will require

support not just from government but also industry and the V&C sector, as Action Mental Health notes:

“The voluntary and community sector have vast expertise to offer in respect of services for this service user group particularly in the areas of day opportunities, training and employment.” – Action Mental Health

Self-directed support

Approval for self-directed support and individual budgets stood at 76% from those who answered question 3 of the *Vision to Action* consultation questionnaire, with Positive Futures stating that:

“We agree that this should be a priority for future development and recognise the complexities that this development will mean for individuals with a learning disability and their families wanting to pursue this option.” – Positive Futures

While there was support for the policy, respondents expressed a number of doubts that must be addressed; self-directed support is not appropriate for everyone with learning disabilities, there are concerns around the capacity of some carers to manage the budget, and worries that this may become an added burden to administer. The Patient Client Council noted that at present there is a clear difficulty accessing individual budgets, and a need for more information and support to uptake the scheme:

“Some people said they either has difficulty accessing them or had never heard the term before” – The Peoples Priorities for Transforming Your Care 2012 (Patient Client Council).

5.7.3 HSCB Response

There was broad agreement with the proposals contained within *Vision to Action*, and in developing detailed plans (subject to Minister’s approval to proceed), we believe particular consideration is required for the following:

- In order to facilitate the independence of people with learning disabilities and carers a special focus needs to be made to simplify services and care pathways.
- Continued and enhanced engagement with service users in the design of services, particularly where these are cross-Programmes of Care, such as Learning Disability services for older people and children.

- Creating age appropriate day opportunities for people with learning disabilities was a key proposal set out in *Vision to Action*. The issue was a recurring theme from respondents. We will consider how greater emphasis needs to be placed on this beyond day opportunities when commissioning services.
- Specific work needs to be done around the issues of the transition from children to adult services, and the growing need for services for older people with learning disability.

5.8 Physical Disability and Sensory Impairment

5.8.1 TYC: Vision to Action Key Proposals

1. Undertake reviews of the current provision of day-care services with the aim of developing **alternative ways to provide day activities**.
2. Put in place more, and a **wider range of, respite** options for carers.
3. Increase the number of people with **self-directed support and individual budgets** to allow them to have more choice about what services they receive.
4. Examine the potential for the development of **specialist supported living options**, for example for those people with acquired brain injury.
5. Enabling individuals to live at home requires a **mixed economy** of service providers to include community and voluntary, private and statutory sectors. Services will be procured to deliver this outcome. This signals a larger role for both the voluntary and private sectors in future. Looking towards this, we will undertake a review to accurately cost such services to ensure value for money and high quality services.

5.8.2 What people told us

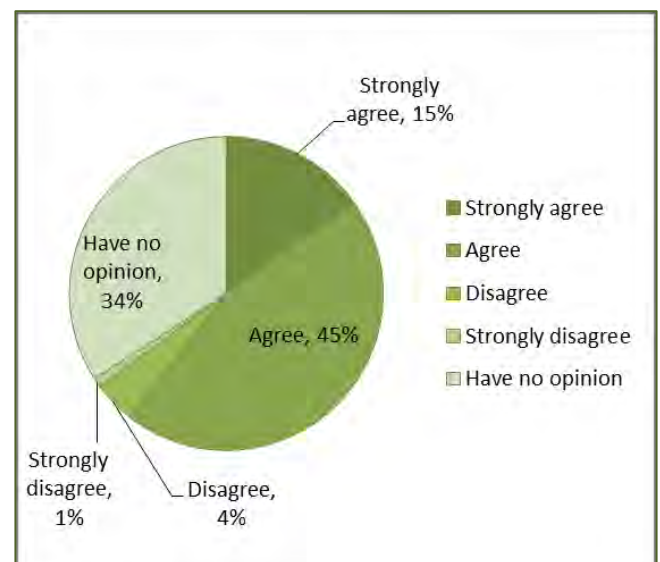
We asked:

Do you agree with the proposals set out in respect of physical disability and sensory impairment services? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 211 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **92% agreed or strongly agreed with the proposals**
- **8% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

The majority of responses received demonstrated considerable support to progress with the proposals outlined in the consultation document, including those from groups representing service users with physical disability and sensory impairment. For example, the Royal National Institute of Blind People (Northern Ireland) commented:

“RNIB supports the proposals for people with physical and sensory disability contained in TYC. RNIB is actively engaged with the health and social care sector and other community and voluntary sector stakeholders in implementation of the Physical and Sensory Disability Strategy. We would hope that over the next 3 years, many of the issues which frustrate disabled people will be satisfactorily addressed and that in particular the joint planning of services by a wide range of stakeholders including the community and voluntary sector will lead to better co-ordination of services, and a wider range of services which will support greater choice and control for disabled people.” - RNIB

Action on Hearing Loss commented:

“Action on Hearing Loss warmly welcomes the Transforming Your Care document and the recommendations made in it. We support the move towards better home- and community-based care.” - Action on Hearing Loss

Many of the comments received with regards to these proposals set out suggestions for how it would be further improved, most notably the need for specific action plans. In this regard, there was consensus that TYC should work in tandem with the implementation of the Physical and Sensory Disability Strategy and it was suggested that an associated action plan should be published along with details of the dedicated investment into these services.

It was emphasised that it is crucial that people with physical disability and sensory impairments are effectively engaged in the design and implementation of services, as well as greater levels of joint planning across the sector. Although one respondent questioned the greater involvement of the Voluntary and Community sector in terms of the regulation and quality of services.

Illustrative comments include:

"This is the opportunity to transform our care not reinstate old and bad practices of excluding disabled people from decision making processes" - North West Forum for People with Disabilities

"Joint planning for people with physical disability across government departments and Voluntary and Community organisations will be necessary in order to achieve the key elements of personalisation, independence and control identified in TYC" - The Peoples Priorities for Transforming Your Care 2012 (Patient Client Council).

It was suggested that there is a need for engagement with the deaf and visually impaired community with regard to public health messages where standard formats may not be appropriate.

Some respondents highlighted the need for dedicated mental health support for people with sensory impairment and physical disability. It was suggested that there is a need for more vocational support for people with physical and sensory disabilities and a greater focus on supporting people to access leisure activities.

The impact of Welfare Reform will be considerable for this service user group and must be taken account of in the implementation process. There was also a request to have regard to access to public transport in more rural areas for this service user group.

There was support for greater use of assistive technology to allow people with physical disability and sensory impairment to live independently but some caution was expressed around ensuring this does not lead to greater social isolation.

The Patient Client Council in their report on the People's Priorities for Transforming Your Care assert that improvement is needed to reduce long waiting times for equipment and home adaptations to support people with disabilities to live independently.

5.8.3 HSCB Response

Of those who expressed an opinion and commented on the proposals in relation to Physical Disability and Sensory Impairment, there was strong support for the proposals. Therefore, subject to the approval of the Minister, in taking forward the implementation of these proposals, having

regard to what we have heard, we will be particularly mindful of the following:

- Continued and enhanced engagement with service users in the design of services, particularly where these are across Programmes of Care.
- In undertaking reviews of current provision of day-care services (proposal 1), include a focus on the provision of more vocational support and rehabilitation to those with physical disability and sensory impairment.
- The need to consider how better collaborative planning of services can be achieved across government departments.

5.9 Family and Child Care

5.9.1 TYC: Vision to Action Key Proposals

1. Promotion of a **multi-agency / partnership approach** to prevent children having to be separated from their families and enable some children to remain safely with their families. Where children cannot remain with their family, alternative arrangements to bring permanency in the best interests of the child will be made.
2. Embed **Family Support Hubs** across Northern Ireland to focus on early intervention. An emphasis should be placed on two key areas: the promotion of positive parenting and positive speech and language communication skills for all our children.
3. **Increase the number of foster carers**, and in particular specialist foster carers for those children and young people who are deemed hardest to place, and present significant challenges.
4. Engage with **Strategic Regional Review of Residential Care Services for Children and Young People** to take forward recommendations of local review in line with regional recommendations. Reduce the reliance on **residential care homes**.
5. Continue to improve the **Child and Adolescent Mental Health Services (CAMHS)**, to reduce the number of children waiting for service and a reduction in waiting times.
6. Increase availability of **emergency CAMHS** cover to avoid acute admissions.

5.9.2 What people told us

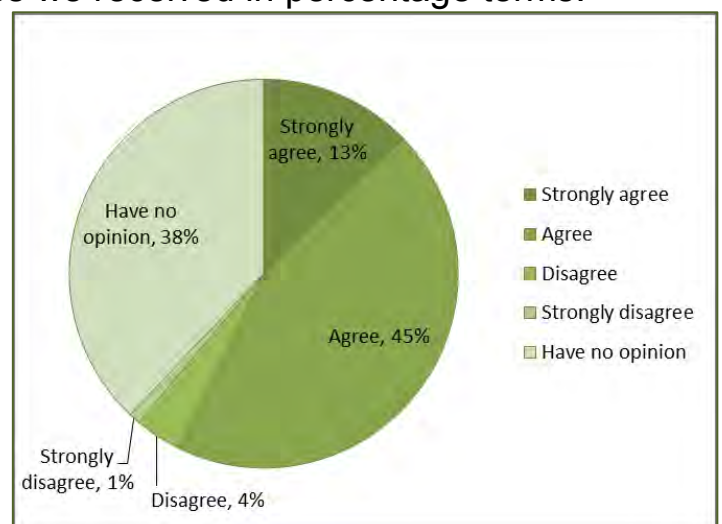
We asked:

Do you agree with the proposals set out in respect of Family and Child Care? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 211 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **92% agreed or strongly agreed with the proposals**
- **8% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

Multi-agency/partnership approach

There was a strong view expressed from respondents that the proposal to promote a multi-agency / partnership approach to help prevent children being separated from their parents was the correct way forward.

“The promotion of a multi-agency /partnership approach to provide services which support a more stable and secure situation for children is vital.” - Northern Ireland Music Therapy Trust

It was widely agreed that, where appropriate, families are the best environment to bring up children. To fully support the proposal it was felt that the focus should be on early intervention and prevention.

Respondents felt that if the emphasis is placed on early intervention and prevention this could help families / children avoid entering into the care system in the first instance. References were made to the fact that the terms “intervention” and “prevention” should not solely refer to acute services but also to social care. However, the Northern Ireland Association of Social Workers did highlight the fact that social workers often do not get to spend as much time as they would like doing proactive preventative work due to the large volumes of paperwork they navigate on a daily basis.

In addition, some respondents talked about the multi-agency approach with regards to the need for greater levels of joined up government.

“An integrated approach will be crucial to the success of an integrated early intervention agenda” - Save the Children

One respondent emphasised the role of the school:

“Schools can be at the centre of a 'multi-agency' approach with possibly the appointment of a senior family support worker as part of the senior management team of each school... That person can then support families locally with positive parenting strategies and signpost to services within other agencies.” - Individual Response

Others mentioned the need to address the needs of children across departments:

“HSCB [should] identify as a priority how it will work meaningfully with those agencies and Departments, such as the Departments of Education, Social Development and the First and Deputy First Minister, to progress the proposals in Vision to Action. Such an integrated approach will be

crucial to the success of an integrated early intervention agenda” - Save the Children

Family Support Hubs

There was a welcome by many organisations and individuals for the development of Family Support Hubs to support early intervention. Respondents felt that they would have a positive impact on parenting skills and the development of speech and language in young people.

“We agree that promoting and supporting positive, engaged parenting for all families is key towards improved communication and bonding” - Early Years

It was suggested that investment in this type of early intervention could help save money in the future and also relieve the burden on adult services as it,

“predicts better outcomes in adult life thus relieving the burden on adult services” - NI Social Care Council

It was suggested that Family Support Hubs could improve access for parents to specific resources for parenting a child with a particular need. Northern Ireland Social Care Council (NISCC) was one of the many organisations that welcomed Family Support Hubs suggesting that this type of early intervention is a positive development.

Foster Carers

There was wide agreement for increasing the number of foster parents. It was highlighted how the life outcomes for children cared for by foster families are significantly better than for those who are raised in residential care. Therefore it was felt that impetus should be given to continuing to engage with the Strategic Regional Review of Residential Care Services for Children and Young People and reduce the reliance on residential care homes.

Voice of Young People in Care (VOYPIC) highlighted that the increase in foster parents would be beneficial especially for those children who are hard to place. Such as:

- young parents in care;
- bail placements; and
- short term and emergency placements.

A few respondents felt that the fostering process was unnecessarily complicated and suggested this discourages people from taking up this role.

Child and Adolescent Mental Health Services (CAMHS)

There was overwhelming support for continuing to improve Child and Adolescent Mental Health Services (CAMHS). Respondents felt that CAMHS at present are underfunded and there needs to be a greater investment in these services. Many respondents felt that investment in early intervention and prevention in CAMHS would enable better outcomes, and reduce demand in the future for adult Mental Health services.

“Contemporary evidence suggests that investment in prevention and early intervention approach saves significant money in the long term and benefits society as a whole” - National Children’s Bureau NI

Respondents agreed with the proposal that there is a need to increase emergency CAMHS in particular. It was also suggested that by increasing the investment in early intervention and prevention this could help reduce the level of crisis intervention needed in the future.

It was noted there is a need for more effective joined up and consistent working between CAMHS and GP primary care providers. It was recognised that there are examples of good joined up government in this area and it should be built upon, particularly in ‘upskilling’ the education sector and parents.

5.9.3 HSCB Response

Of those who expressed an opinion about the proposals for Family and Child Care, there was strong agreement with the proposed way forward. As with many of the other Programmes of Care, many of the comments related to what respondents see as priorities to ensure that these are successfully implemented, and areas where attention should be given in doing so. In particular the need for investment in early intervention and early years services, better joined up government and further development of CAMHS came across strongly in this section.

Subject to approval of the Minister to proceed, in developing the implementation plans, detailed responses and comments will be taken into account, for example we will be particularly mindful to the emphasis on early intervention and prevention, and seeking ways in which Family Support Hubs can take a role in signposting families with particular needs to the correct pathways of care.

5.10 Maternity and Child Health

5.10.1 TYC: Vision to Action Key Proposals

In respect of maternity services, key proposals were:

1. Promote **normalisation of birth** - bringing ante-natal and post-natal visits into line with best practice and NICE guidance, and improving access to midwives as initial point of access.
2. Reduce the length of time mothers **stay in hospital**, where appropriate.
3. **Increase the number of women** having their ante-natal care in the community, rather than attending hospitals.
4. Improve **ante-natal education** and **early parenting** to promote good parent/child relationships in the early years.

In terms of the configuration of maternity units, **the following was proposed:**

1. In the **Belfast** area, a freestanding midwife-led unit would be developed in the Mater Hospital, with one consultant-led obstetric unit in the Royal Jubilee Maternity Hospital. We also plan to provide an 'alongside' midwife-led unit in the new regional maternity hospital.
2. In the **Northern** area, initially the current services will remain at both Causeway and Antrim Hospitals. The volume of activity in the consultant obstetric unit in the Causeway Hospital will be reviewed to ensure it meets the required standard. Given the likely number of births at the Causeway Hospital it is probable that there would be change in obstetric services at the Causeway Hospital over the next 3 to 5 years as it is not likely to be possible to maintain a safe and sustainable consultant-led service there.
3. In the **South Eastern** area, there would continue to be a consultant-led obstetric unit and an 'alongside' midwife-led unit at the Ulster Hospital, with freestanding midwife led units in Downe and Lagan Valley Hospitals. These units are to be reviewed over the next 3 to 5 years to ensure their continuance is demonstrably supported by mothers choosing to use them.
4. In the **Southern** area, there would continue to be a consultant-led obstetric unit and an 'alongside' midwife unit at Craigavon Hospital, and a consultant-led obstetric unit in Daisy Hill hospital. The level of medical cover for the consultant-led obstetric unit in Daisy Hill Hospital would continue to be reviewed to ensure it meets the required standard. An 'alongside' midwife-led unit would also be developed at Daisy Hill Hospital.

5. In the **Western** area, there would continue to be consultant-led and midwife-led units in both Altnagelvin Hospital and the South West Acute Hospital. The level of medical cover for the consultant-led obstetric unit in the South West Acute Hospital would be reviewed to ensure it meets the required standard. It is likely there will be additional activity from the Republic of Ireland.

In respect of Child Health, the key proposals were:

1. Establish **Family Nurse Partnership Programme** pilots; in the first instance these will be in 3 specified areas (Western, Southern and Belfast), to improve the health and wellbeing of our most disadvantaged children and families, thus preventing social exclusion.
2. When children require **hospital care** they need prompt access to skilled staff. It is not possible to provide a full range of paediatric sub specialities for a population the size of Northern Ireland and therefore we will continue to ensure there are arrangements in place when families have to access services in other parts of the UK or when services are not available locally.
3. There is a need to move towards admitting all children under the age of 16 to age appropriate paediatric settings. The DHSSPS will be starting a **review of acute paediatric services**. A review of paediatric palliative and end of life care services will follow. This will facilitate a regional approach to how services should be organised in future, including agreement on the age of transfer from paediatric to adult services.

5.10.2 What people told us

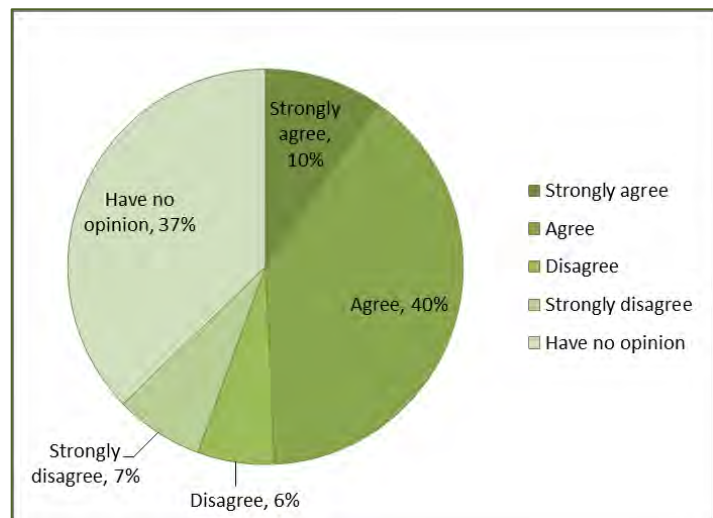
We asked:

Do you agree with the proposals we have set out in respect of maternity and child health services? Do you believe there are better alternatives?

Of the 254 questionnaire responses, 207 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **78% agreed or strongly agreed with the proposals**
- **22% disagreed or strongly disagreed**



A number of themes can be drawn out from the comments we received about the proposals in relation to Maternity Services:

Normalisation of Birth

Overall, respondents welcomed the proposals for the normalisation of births.

The proposal for moving antenatal care to the community was received very positively as long as the care is adequately planned and resourced. Respondents felt that antenatal care provided in the community would create better outcomes for mothers and babies as more mothers would attend routine appointments.

Some respondents felt that more consideration was needed to be given to the proposal of reducing the length of stay particularly for first time mothers and those with specific maternal vulnerabilities. The Northern Ireland Practice and Education Council for Nursing and Midwifery stated that

“timely discharge from hospital is appropriate for mother and baby...however should be managed on an individual basis.”-NIPEC

Antenatal Education and early parenting

Respondents liked the idea of improving antenatal education and early parenting care. It was felt that good health begins before birth and there was a high importance for good easily available pre-conception care, advice, information and support. Some respondents felt that by placing an even greater focus on pre-conception care for example promoting physical activity, healthy diet, stopping smoking, reducing alcohol intake this will reduce the burden on paediatric services in the long term. There was a welcome to the commitment to promote and support positive, engaged parenting particularly in those families where parenting skills are limited.

Configuration of Maternity Units

Royal College of Midwives agreed with proposals regarding the regional configuration of maternity units, and endorsed the view that any future changes should be planned and managed with full engagement:

“we support the proposals...however we seek assurance that any future change in service configuration will be managed in a timely fashion.” - Royal College of Midwives

However, there were some concerns about the proposed freestanding midwifery led units from some respondents. The British Medical Association disagree with the implementation of freestanding maternity units saying

“evidence of safety of midwifery led units is lacking” - BMA

However respondents were generally positive about midwifery led units when on the same site or in close proximity to a consultant led obstetric unit.

There was strong support from a small number of respondents for retaining full obstetric led services at Causeway Hospital.

It was also noted that the on-going reviews of paediatrics services by the DHSSPS may impact on maternity services.

“any changes in paediatric care provisions across regional, district and general hospitals such as in neonatal care will directly impact on maternity services” - NI Commission for Children and Young People

In addition to the proposals set out in *Vision to Action*, it was suggested by a number of respondents that Northern Ireland would need a full inpatient perinatal mental health unit for mothers and babies. The Royal College of Psychiatrists stated that Northern Ireland currently “lags behind” in perinatal psychiatry and The Royal College of Midwives argue that

“further and urgent consideration should be given to the development of an inpatient perinatal mental health facility from women in Northern Ireland” – Royal College of Midwives

In addition to the quantitative data shown above which covered maternity and child health proposals, a number of themes can be drawn out from the comments we received about the proposals in relation to Child Health:

Family Nurse Partnerships

There was a welcome from many for Family Nurse Partnerships (FNPs) with respondents stating that they would like to see them extended further as they promote positive parent/ child interactions especially for families where parenting skills are limited. It was also recognised that these are currently in development phase.

“...we look forward to the wider roll out of this programme to support vulnerable young mothers...” – National Children’s Bureau NI

Review of acute paediatric services

There was a general agreement on the need to move towards admitting children under the age of 16 to age appropriate paediatric settings. Concern was expressed around the lack of inpatient facilities for children who have to go to adult wards. The Northern Ireland Children’s Hospice highlighted the fact that, due to advances in treatment, many children with life limiting conditions are living longer and may now survive into adulthood, therefore there needs to be a smooth and managed transfer of their health and other care needs to adult services and this is challenging. They also showed support for the review of acute paediatric and end of life services and

“support the aspiration to develop a regional approach to the future organisation of services” – Northern Ireland Children’s Hospice

Paediatric Sub specialities

There was a small number of responses commenting on the on-going Paediatric Cardiac Congenital Services consultation expressing the wish for full cardiac services to remain in Northern Ireland.

Other Comments

The Northern Ireland Commissioner for Children and Young People raised the fact that health professionals often fail to; actively engage children in decisions about their health, provide information to children, or to understand children's capacity to make decisions and give consent. They call for health professionals to be mindful of the rights of the child and encourage children and young people to be actively involved in decision making in accordance with age and maturity.

5.10.3 *HSCB Response*

Of those that expressed an opinion in regard to the proposals for Maternity and Child Health services, there was broad support for the direction of travel and the proposals as a way of achieving the aims set out. Subject to approval of the Minister to proceed, as we develop detailed implementation plans, we will be particularly mindful of the need to;

- Continue to promote the normalisation of birth and community services for ante-natal care, supported by seeking to ensure that the number of community midwives are commensurate to demand (this will be part of the workforce planning work described in Part 4.4).
- Conduct further consultation and engagement on future changes to hospital maternity services – this will be particularly relevant with regard to freestanding midwife led units.
- Subject to the evidence from the pilots in the West, South and Belfast areas, seek the rollout of Family Nurse Partnership Programme regionally.
- Ensure the outcomes of the forthcoming Review of Acute Paediatric Services, and further reviews to be undertaken, are reflected in future plans.

In addition, the HSCB has already embarked on a scoping exercise for a regional perinatal mother and baby unit, and as part of this we will review the views on this matter expressed during this consultation.

5.11 Acute Care in Hospitals

5.11.1 TYC: Vision to Action Key Proposals

With regards to regional services the key proposals were:

1. Making sure everyone has 24-hour access to safe, sustainable cardiac **catheterisation laboratory services** – including the introduction of an (emergency) primary Percutaneous Coronary Intervention service, which is a milestone of the Northern Ireland Executive’s Programme for Government – with an associated investment of up to £8m over the next three years. Two sites would be developed: one in Altnagelvin Hospital and the other in Royal Victoria Hospital.
2. Expansion of **orthopaedic** services in Southern, Western and Belfast Trusts with an investment of up to £7m revenue over the next 3 years, to significantly reduce waiting times for fracture and other orthopaedic services for patients.
3. To ensure safe, sustainable arrangements are in place for the provision of **Paediatric Congenital Cardiac Surgery** and **Paediatric Interventional Cardiology** for the population of Northern Ireland.
4. The DHSSPS will be carrying out a **review of paediatric services**, with a view to beginning consultation within 6 months. A review of palliative and end of life paediatric services will follow.
5. Our **Ambulance** services will continue to develop new protocols which support “right care, right place, right time, right outcome”. Protocols will be outcome-driven and reflect best practice. They will provide alternatives to going to hospital, support people to safely manage their health at home (where appropriate), and take patients without delay to the most clinically appropriate destination.

This means that sometimes a patient may not be taken to the closest Emergency Department but be taken directly to a facility they have been to before, or be taken to a hospital which is not the one closest one but specialises in treating their condition.

Key initiatives include looking at the feasibility of:

- A “111” urgent care service sitting alongside “999” – simplified access to urgent care 24/7 with real-time clinical advice and direction/support in accessing healthcare.
- Hospital-at-home protocols with suitably trained and equipped ambulance, hospital and community based clinicians organising and providing clinical assessment and treatment in settings other than hospital.

6. Enhance the dedicated paediatric and neonatal transport services throughout Northern Ireland.

In relation to each area, the key proposals were:

1. In **Belfast** the hospitals, comprising Royal Victoria Hospital, Belfast City Hospital, the Mater Hospital and Musgrave Park Hospital, would operate as one network with clinical services dispersed across the sites in the best configuration available. Specifically recent consultation recommends one emergency surgery centre at the Royal Victoria Hospital. Emergency department configuration across the network will be consulted on in 2012.

2. The principal hospital in the current **Northern** network is Antrim. It would continue to deliver all core general hospital services – surgery, medical, emergency department, maternity, renal etc. – responding to its natural population area. A large number of people using Antrim Area Hospital live in the greater Belfast area. Network arrangements need to reflect this and ensure appropriate links with Belfast Hospitals.

The need to ensure that acute hospitals are providing safe and high quality services and the natural population flows in the area means that change will occur on the Causeway site in terms of its core in-patient services. There would be access to 24/7 emergency/urgent care on both Antrim and Causeway sites, which would be doctor led. We need to responsibly manage this change over the next 3-5 years.

In that context, any decisions about the networking and future services in Causeway Hospital reflect a strong commitment to the continuing local role for the hospital, but also enable it to benefit fully from being networked with other hospitals.

There will always be some degree of networking between Causeway and both Antrim Area and Altnagelvin Hospitals across the wide range of services, as there is at the moment. However, in planning the organisation of our services, we should consider which formal networking arrangement would have greatest benefit to the population served by the Causeway Hospital and to ensure effective delivery of safe, sustainable and resilient services for patients and clients.

One option is to focus on developing existing networking arrangements with Antrim Area Hospital. However, given the future changes which are likely to occur in services at Altnagelvin, such as increased radiotherapy, cardiology and orthopaedics, and consequently the likely natural flow towards Altnagelvin, it may be better to develop a more formal network between Causeway and Altnagelvin.

There would in effect be three options:

(a) An enhanced network with more formalised integrated working between Causeway and Antrim Area Hospitals, with the Causeway Hospital remaining the responsibility of the Northern Trust.

(b) An enhanced network with more formalised integrated working between Causeway and Altnagelvin Hospitals with the Causeway Hospital remaining the responsibility of the Northern Trust.

(c) An enhanced network with more formalised integrated working, between Causeway and Altnagelvin hospitals with the Causeway Hospital becoming the responsibility of the Western Trust. Consideration could also be given to the transfer of community services for the population served by Causeway Hospital to the Western Trust.

Looking to the future an appraisal of the implications of each of the above options should be undertaken. It is envisaged that a final decision would be made within 6 months of the close of consultation.

3. In the **Southern** area, there is already strong evidence to suggest that changes have occurred across Craigavon Area Hospital and Daisy Hill Hospital which demonstrate robust networking. This includes a network of medical staff which supports the provision of safe, quality care for more acutely ill patients in the High Dependency Unit in Daisy Hill Hospital, through 'virtual wards rounds' with specialist medical staff based in the Intensive Care Unit in Craigavon Area Hospital. They use new technology which means that the specialist is involved in clinical decision making and can talk to patients and families, as if they were physically present. There is also a networked approach to Emergency Departments to ensure that service is safe and sustainable on both sites at all times through shared protocols

and management. This model is to be supported and encouraged, and it is expected that further sensible changes will occur to maximise the effectiveness of this network in line with the criteria for acute care.

4. In the **South Eastern area** there is a principal hospital network encompassing the three hospitals – Ulster Hospital, Downe Hospital and Lagan Valley Hospital with clinical activity dispersed across the 3 sites. The Ulster Hospital will have 24/7 Emergency department and the full range of normal acute hospital services. The urgent care model operating at Downe Hospital covered by GP out of hours would continue and it is proposed that this would be extended to Lagan Valley Hospital.

Of equal importance is the network between the South East and Belfast. This is most obvious in a flow from Lisburn to Belfast and from east Belfast to the Ulster Hospital. This networking is to be supported and encouraged. Looking to the future the evolving network will continue to use the criteria to shape service provision.

5. The **Western area** has two acute hospitals – the new South West Acute Hospital in Enniskillen and Altnagelvin in Londonderry. The South West Acute Hospital will reflect the needs of its population areas including the dispersed rural population and provide all general hospital services. Altnagelvin Hospital will in future provide a wider range of specialist regional services, including future investment in orthopaedics and cardiology, and cancer services from 2016. Altnagelvin will continue to network with Causeway Hospital and Antrim Area Hospital as appropriate.

The South West Acute Hospital would network strongly with both Altnagelvin and with Craigavon Area Hospital in the Southern area. This reflects natural population flows and takes account of planned specialist service developments.

5.11.2 What people told us

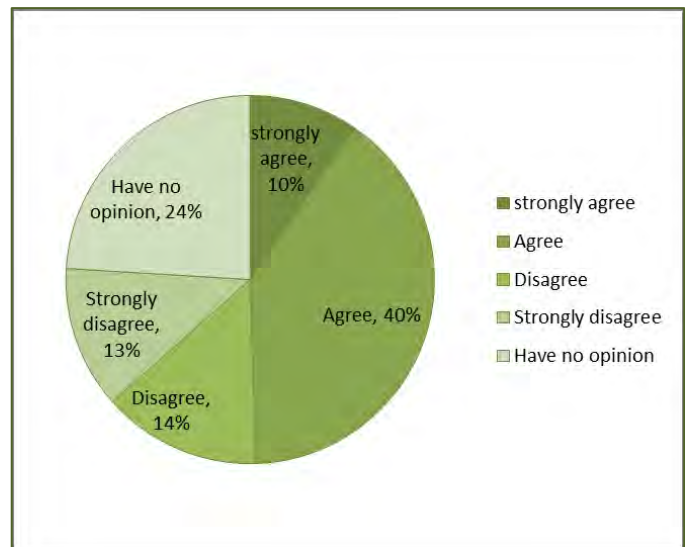
We asked two questions in relation to Acute Hospital Services:

1. *Do you agree with the proposals set out in respect of acute hospital services? Do you believe there are better alternatives?*

Of the 254 questionnaire responses, 208 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **66% agreed or strongly agreed with the proposals.**
- **34% disagreed or strongly disagreed.**



2. Do you agree that the criteria set out in Appendix 1 against which acute services have been assessed remain the most appropriate criteria?

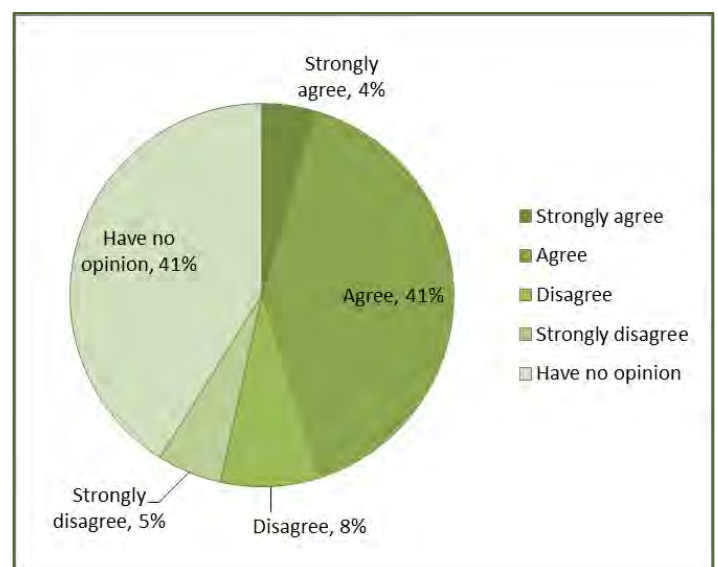
If you disagree or strongly disagree, please provide specific details on what you see are more appropriate criteria. Please give reasons for your comments.

Of the 254 questionnaire responses, 202 answered this question. The graph below sets out all the responses we received in percentage terms

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **77% agreed or strongly agreed with the criteria.**
- **23% disagreed or strongly disagreed**

In addition, a number of themes can be drawn out from the comments we received about these proposals:



There was general support for the need to review acute hospital configuration and investment in specialties was warmly welcomed and recognised. Of those who expressed an opinion via the questionnaire, 66% agreed with the proposals, with some saying that we are over-reliant on too many acute hospitals, and others saying that these are necessary changes which should be done in a managed way rather than through response to crisis, which could mean that community and other services will not be adequately equipped.

A number of respondents felt that there was a need for more clarity on what hospital networks mean and how they will operate. It was also evident in some responses that there may be some confusion that the proposal for 5-7 hospital networks was interpreted as 5-7 acute hospitals – it is not the case that *Vision to Action* proposed to close acute hospitals. Although some respondents did promote the need to reduce the number of acute hospitals.

“Agree. NI has too many acute hospitals. The service should be designed to provide the best sustainable clinical solution that is as accessible, within geographic constraints.” - Individual Response

Overall, safety and quality of services, was paramount for many respondents.

The Patient Client Council commented:

“People are concerned about the future of hospital care and treatment. They want to be assured that their families have access to hospital services within a reasonable timescale and be assured of the quality of care they can expect” - The Peoples Priorities for Transforming Your Care 2012 (Patient Client Council).

There is clear evidence of a need to engage with the public in the implementation of any changes to acute hospitals and community based services if real change in the pattern of acute services is to be achieved.

“There needs to be a clear communication to the public about the profile of services available for each hospital and how they access them” - Western Health and Social Care Trust

Whilst some expressed an anxiety that they may need to travel further for some specialities, others recognised that increasing specialisation meant hospitals needed to work in networks, and not all services would be available everywhere:

“Agree, young people are willing to travel further as long as the treatment is better” - Barnardos

A strong emphasis emerged of the need to take account of access to acute hospitals for rural communities and emphasised that a critical enabler would be improvement of public transport access and the road network. This issue was raised at the public meetings and was also reflected in written responses received.

There was a significant welcome for development of more local and community based services especially among those in rural areas.

In general respondents called for changes to acute hospitals to be planned and managed effectively and for alternatives in the community to be in place and working effectively before changes are made.

“Investment in local services and community alternatives and ICPs will make the transition to fewer acute hospitals possible” - Individual Response

There were some perceptions that the proposals would result in a reduction in accessing acute care at a time when A&E services are already under pressure and that there should instead be an investment in front line staff and a reduction in management costs.

Also in relation to staff and resources, it was proposed that a robust medical workforce strategy should be developed to keep acute facilities operational into the future. There was support for implementing seven day a week services in acute hospitals as well as networking with other sites in the locality. The Royal College of Nursing felt it was important to clarify the patient flow and staffing within networks (particularly Causeway Hospital).

It was suggested that there should be a greater focus on the impact changes in the acute hospital configuration will have on the NI Ambulance Service. Many respondents highlighted that the success of reconfiguring hospital services will be dependent on a fully resourced and responsive ambulance service. This was especially important to those living in rural areas where some respondents felt that the ambulance service is currently under pressure to meet targets and worried that response times could suffer if proposed changes to acute services are implemented.

It was proposed by some clinical respondents that acute diagnostic accuracy is a major clinical and financial problem and more emphasis on diagnostic accuracy would improve all aspects of the health service.

There were very few responses which addressed the proposals for introduction of the Urgent Care “111” service but there was some concern expressed by one of the professional groups that this would have significant impacts on primary care as evidenced in England.

Local Proposals

Often local issues dominated responses and discussion at public and stakeholder meetings, and were raised with regard to maintaining or re-instating full acute services at Causeway Area Hospital, Mid Ulster Hospital and the lack of acute facility in Tyrone, specifically Omagh. These issues were very strongly highlighted in those localities and those present emphasised how important a fully functioning Emergency Department and acute hospital was to them.

The single issue which prompted the most responses was in relation to Causeway Hospital, in the Northern Area, which formed the basis of nearly 70% of overall responses. These were single issue responses, focussing mainly on the Causeway area, in one of three standard letter formats signed and submitted by individuals. This highlighted the strength of local feeling. A copy of the text of these letters can be found in Annex 4.

All of these letters wished to emphasise the need for full acute services at Causeway Hospital. The majority of these (1,506) supported the option to transfer management of the Causeway Area Hospital to the Western Health & Social Care Trust to allow better networking with Altnagelvin hospital. Coleraine Borough Council was in support of further appraisal of the options for the future. The Causeway Hospital Medical Staff Committee commented:

“Causeway Hospital Medical Staff see the TYC proposals as an opportunity to create improved care networks for the local population and create safe, sustainable and resilient service for the future... In the opinion of Medical Staff, enhanced networking with Altnagelvin with Causeway becoming the responsibility of the Western Trust is an option that must be fully explored” – Causeway Hospital Medical Staff Committee

This can be contrasted with the views of the Northern Trust which set out its view for maintaining the current arrangements for both acute and community services.

It was also emphasised by many that if management of the Causeway hospital transfers to the Western Trust it is vital that the community services for that locality also transfer. In relation to other local proposals the following was noted:

- In relation to proposed investment in cardiac catheterisation, the South Eastern Trust comments that TYC does not make reference to the regional review which has been deferred for 18-24 months; also they argued for the inclusion of acute catheterisation lab services for Ulster Hospital. In addition they wished to see reference to development of orthopaedic services at the Ulster Hospital.
- There were a number of respondents who referred specifically to the Northern Trust in terms of performance and current services. This includes some of the Councils in that area, and other interest groups (for example 'Save the Mid'). Some of these responses highlighted current service issues, and did not feel that the proposals address these sufficiently.
- In the Southern Area, there was welcome for greater networking and the security that this gives to Daisy Hill Hospital. Given the rural nature of the area and poor roads infrastructure it is essential that services are retained and enhanced at Daisy Hill, supported by Ambulance services.
- In the Western Area, the main concerns expressed were the lack of profile given in the proposals and plans to the new enhanced local hospital in Omagh and its role in future.
- There was general support for the networking of Belfast hospitals although the response from the Mater Hospital Trustees did emphasise their position that in order to meet the needs of the North Belfast population, general medical and support services must be maintained on the Mater hospital site including a twenty-four hour A&E unit.

Acute criteria

Very few respondents commented specifically on the criteria set out in the document against which acute services have been assessed. One respondent wished to see more rationale behind the criteria.

Many of those who did comment on the acute criteria generally agreed with those proposed and supported their use in assessing acute services. There was a view that 'Local Access' and 'Stakeholder Support' should have more weight within the criteria.

It was proposed that patient outcomes should also be a critical indicator as well as safety and quality, and that retention of a skilled workforce should also feature as a key criterion (this is already contained under 'Deliverability and Sustainability').

5.11.3 HSCB Response

Following consideration of the responses to the proposals for acute hospital services, this would indicate that a more detailed Options Appraisal on the future of management arrangements for Causeway Hospital should go forward with a view to completing this appraisal within 6 months. The responses also indicated this should include consideration of community services.

Subject to approval of the Minister to proceed, in moving forward with developing detailed plans for acute hospital services, we also recognise that the following will be particularly important in response to what we have heard:

- Workforce development plans which are to be developed to underpin TYC should take account of the call for more '7 day a week' services to be commissioned.
- Ensure that there is clear and widespread communication to clarify what is meant by a hospital network, emphasising that TYC does not propose 5-7 hospitals but rather 5-7 hospital networks, and what this will mean for the public, both regionally and locally.
- Ensure that communication plans make clear the investment and progress in local services and community alternatives via ICPs and intermediate care.

In addition, the need to consider how better collaborative planning of public services relevant to the access to acute services for rural communities and the improvement of public transport links, can be achieved across government departments, as set out in proposals in the original TYC report.

5.12 Increasing links with Republic of Ireland and Great Britain

5.12.1 TYC: Vision to Action Key Proposals

1. Create more formal contractual arrangements with the Republic of Ireland to reflect this pattern of care.
2. Establish closer planning links to enable the achievement of best outcomes for citizens

5.12.2 What people told us

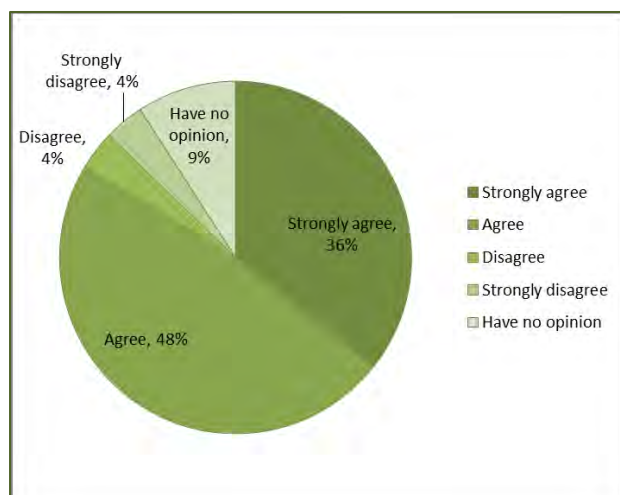
We asked:

To what extent do you agree we should develop closer working relationships with the Republic of Ireland and Great Britain?

Of the 254 questionnaire responses, 219 answered this question. The graph below sets out all the responses we received in percentage terms.

The statistical analysis of the responses to this question show that of those who expressed an opinion:

- **92% agreed or strongly agreed**
- **8% disagreed or strongly disagreed**



In addition, a number of themes can be drawn out from the comments we received about these proposals:

The majority of respondents agreed with *Vision to Action*, and the feedback given was very positive with the overall feeling being that the proposals were logical and sensible. In particular, respondents felt that:

- The sharing of learning between clinicians will ensure that patients can get the best care and expertise and will benefit from the most up to date treatment and knowledge.

"...links are vital for sharing best practice and innovation...."- Ulster Chemist Association

- Respondents welcomed the fact that increasing links can mean a reduction in waiting times for certain procedures and it was generally felt that for very specialist care they did not mind where that care was being received as long as it meant a better outcome and better results for them.

"Break down all barriers and work with whoever is necessary to provide the patient with the service they require to keep them well or to get them well" – Individual Response

- In respect of forging more formal arrangements with other jurisdictions, support was given by a large number of respondents and the new radiotherapy centre in Altnagelvin was mentioned by some as a good example of how this is already happening.

Whilst there was broad agreement there were a number of respondents (8%) who disagreed with the proposals. Various reasons were given, including:

- The impact of travelling to another country for treatment would have on families and the need to be mindful of the huge stress and strain this could place families under. The British Psychological Society stated that

"..the stress caused would complicate an already emotionally challenging situation"- British Psychological Society.

- Concern that we do not have enough resources to support the Northern Irish population therefore we should not have formal arrangements with other jurisdictions.

"NI health service can't support people in Northern Ireland never mind another drain on resources" – Individual Response

Additional Comments

Some respondents felt that although forging links with Great Britain and the Republic of Ireland was good it was important not to overlook Northern Ireland as a centre of excellence and that it is important for Northern Ireland to be able to carry out research and become a pioneer in medical research.

A number of respondents also mentioned the Paediatric Congenital Cardiac Services review being carried out by Health and Social Care Board, and expressed concern that these services would be impacted.

5.12.3 HSCB Response

Given the broad agreement, and subject to approval from the Minister, we propose to move forward with plans for establishing links with the Republic of Ireland and Great Britain as set out in *Vision to Action*, ensuring patient care and outcomes are the priority in doing so.

5.13 Equality and Human Rights

5.13.1 What Vision to Action said

The HSCB undertook an Equality and Human Rights Screening on the proposals set out in *Vision to Action*, and published this as part of the consultation.

One of the stated objectives of TYC and the draft plans is the reduction in health inequalities and the promotion of equality of opportunity. The proposals are not about pausing or stopping changes that are already underway and delivering better outcomes and experiences for patients, staff, service users and carers, but rather TYC seeks to draw these together into a clear and coherent picture.

This means that some of the proposals had already been subject to robust screening and impact assessment as appropriate. Other service changes which are new or represent a significantly different way to provide health and social care services will be subject to all appropriate equality screening and impact assessment.

Also due to the strategic nature of the draft plans, the detail of the approach to implementation has yet to be worked out. As these become known, and further evidence on the nature of the impact on each group becomes clearer Equality Impact Assessments (EQIA) will be undertaken as required and in accordance with our obligations in this regard, and our commitment to promoting equality and human rights.

This document also emphasised that the equality issues identified in response to this consultation exercise will inform future screening and impact assessment exercises.

5.13.2 What people told us

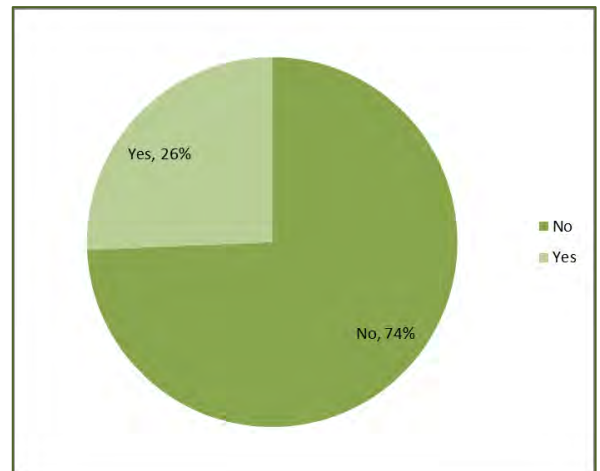
We asked the following four questions:

- 1. Are the 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.*

Of the 254 questionnaire responses, less than half answered this questions (113 responses), although it was also featured in some free-form responses.

The statistical analysis of the responses to this question show that:

- **74%** felt that the proposals were not likely to have an adverse impact on any of the nine equality groups
- **26%** thought it could have an adverse impact

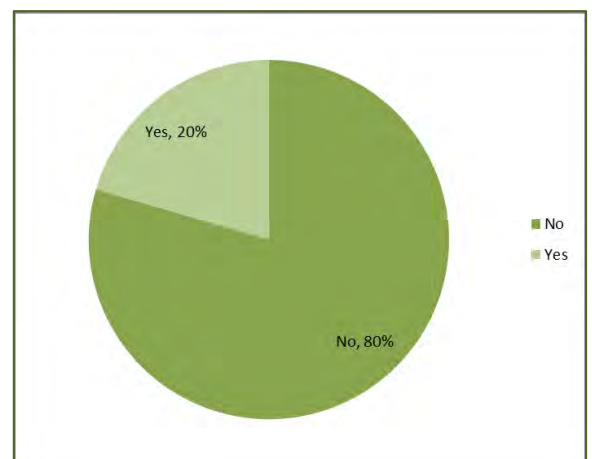


2. *Are you aware of any indication or evidence – qualitative or quantitative – that the proposals set out in this consultation document may have an adverse impact on equality of opportunity or on good relations? If yes, please give details and comment on what you think should be added or removed to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

Of the 254 questionnaire responses, again response rate was low with only 122 answering this question.

The statistical analysis of the responses to this question show that:

- **80%** responded that they were not aware of any evidence that the proposals would have an adverse impact on equality of opportunity or on good relations
- **20%** responded that they were aware of evidence that the proposals would have any adverse impact



3. *Is there an opportunity to better promote equality of opportunity or good relations? Please give details as to how.*

4. *Are there any aspects of the proposals where potential human rights breaches may occur?*

With regards to questions 3 and 4, these were freeform responses with no quantitative data. Comments received have been included in the analysis below.

In addition to the above data, we received comments from some respondents. The themes emerging from these are set out below.

The majority generally indicated, as both graphs above illustrate there would be no obvious breach of human rights or equality obligations as a result of the proposals in *Vision to Action*.

There was agreement with the movement towards a greater emphasis on a human rights approach within Health and Social Care being promoted by the Transforming Your Care agenda. Particularly welcomed were the continued discussions between the HSCB and a number of organisations such as The Northern Ireland Human Rights Commission and Equality Commission, with Northern Ireland Hospice stating the

*“Commitment to on-going dialogue with Northern Ireland Human Rights Commission will assist a Human Rights Based approach”
– NI Hospice*

Of those that made comments in this area, the majority of which were from organisations, there were calls for a full Equality Impact Assessment (EQIA) to be undertaken for the entire TYC programme at the earliest opportunity. Northern Ireland Council for Ethnic Minorities believes that, a full EQIA is required as:

“TYC represents a new strategic direction with particular vision, aims and priorities and thereby represents a fundamental shift in the delivery of all existing health and social care provision.” – NI Council for Ethnic Minorities

Disability Action noted the difficulty responding to this section without an EQIA stating:

“As no evidence is provided in relation to the EQIA the consultee has no research on which to base our comments.” – Disability Action

The Equality Commission welcomed the key principles and intended outcomes in TYC and also welcomed the increasing equality approach and that the plans *“provide an opportunity for the Department (sic) to actively contribute to the progressive realisation of the right to health and social care”*, and also requested that consideration is given to an EQIA *“at this stage or when firmer proposals have been developed at a later stage”*. The HSCB would welcome further discussions with key

stakeholders on how we can best ensure that equality and human rights can continue to be integrated into our plans.

Also the Equality Commission expressed concern that the relevant Departmental templates had not been used. Just to provide clarity on this point, the HSCB used their own screening template, as the *Vision to Action* document covered the service changes proposed by HSCB. We would welcome discussion on this point in future to ensure that we can develop an appropriate framework for the continued screening and assessment of equality issues.

The equality screening was completed using the most up to date data available at the time. However a few respondents have recognised that this data is subject to change with the on-going release of 2011 census data. With the Equality Commission stating:

“We would stress the importance of using the new census data as it is released in order to ensure that equality impacts are accurate.” – Equality Commission

A small number of organisations also made comments with regards to human rights, referencing the international conventions and frameworks that would have relevance to health and social care. Whilst comments do not provide any compelling evidence of human rights breaches, it does give helpful indication of issues we must be mindful of, and the need to explore ways we could potentially further promote human rights. For example, particular comment was made around the rights of children and young people in health and social care by the NI Commissioner for Children and Young People. They said that due regard should be paid to human rights obligations under international law specifically in this case The Convention on the Rights of the Child:

“It is of particular importance that TYC is underpinned by a rights based approach to health and wellbeing; promotes a holistic and life course understanding of health; engages directly with children and young people in relation to both their individual care and broader development and review of services. This should include the participation of vulnerable groups of children and those with particular or complex health and social care needs.”-NICCY

The HSCB continues to engage with the Human Rights Commission to explore how we can take an increasingly human rights based approach.

A small number of individuals raised concerns around privacy. Arising from the use of new technology such as Electronic Care Records and

telemonitoring in health and social care, there will be a requirement for robust data management and security.

Specific comments in relation to s75 equality groups include:

- Women's Support Network and Women's Resource and Development Agency noted that women are more likely than men to have caring responsibilities. The Northern Ireland Society of Social Workers (NISAW) agreed adding that the proposals could *"increase the burden on this section of the community."* Carers NI drew attention particularly to women bringing up their own children while simultaneously caring for a parent.
- The movement of resources from secondary care to primary and community care was noted as having a potentially negative impact on a number of groups who are more likely to access care through the Emergency Department and not through a GP or other primary care. This was mentioned specifically in relation to the traveller community.
- Age discrimination was referred to by a number of respondents, with the Equality Commission making reference, in a stakeholder meeting, to the possible introduction of new age discrimination legislation, and for account to be given to the possible effect of this. Care for the elderly was commonly presented as an area of concern, with a small number of respondents interpreting the reduction of statutory residential care as age discrimination. The disparity between children's and adult services in learning disability has been mentioned by a number of respondents.
- The proposed shift of services into the community led some respondents to highlight worries about the availability of foreign language interpreters and signers for deaf patients.

5.13.3 HSCB Response

As a result of the responses received to this consultation, the HSCB is committed to updating the screening document that developed alongside the draft Strategic Implementation Plan and *Vision to Action* covering those service changes arising from TYC for which HSCB has responsibility. This will take account of the evidence and views expressed to us during this consultation.

Whilst we acknowledge the calls for an EQIA at this point, we remain of the view that it would not be meaningful to conduct an assessment on an overarching strategic vision, rather it would be more meaningful for specific service changes to be subject to full impact assessment as the

specific impact on s75 groups can be fully assessed once detailed plans are known. This view also recognises that some of the proposals have already been subject to screening and EQIA when they were developed as policy. We are therefore not proposing to conduct a full EQIA at this point, but will continue to keep this under review.

The HSCB is committed to both fulfilling our obligations with regards to equality and human rights, and also to integrate an equality and human rights based approach into the design of services in future. Through the TYC implementation therefore we will continue to have on-going dialogue with both the Equality Commission and the Human Rights Commission on how this can be best achieved.

In doing so, we recognise that more could be done to engage people in the debate and concepts of equality and human rights, and we should be seeking to take the lead in engaging the general public on these matters. The low response rate to these questions (which are standard equality and human rights questions commonly used in public consultations) and the finding that many organisations did not comment on this section perhaps indicates that more could be done to build understanding amongst those we are engaging with and consulting. This will be taken into account as we continue to engage and consult during the implementation of TYC.

Part 6. Supporting the Changes to happen: Consultee Response

6.1 Workforce

Due to the responses received in relation to workforce, this has drawn out as an overarching theme, and a discussion of what people told us is set out in Part 4.

6.2 Procurement

The response to Question 5 showed there was broad support for having a mixed economy of service providers for care in the home, although it is also recognised that a significant minority of those responding to this question would prefer this to be provided by statutory bodies.

Many comments received around the subject of procurement highlighted the view that the process should be more accessible to smaller organisations to ensure that their unique contribution could be secured and there is adequate and fair competition. The complexity of the process, the considerable time involved and level of specialist knowledge required means that some smaller groups, particularly within the Voluntary and Community sector, find this restricts their participation or even excludes them altogether from the tendering process because they cannot provide enough people to prepare the necessary details for submission. Some respondents from this field also recognise that the sector needs to do more to build collaborative networks within and across the sector to support their own capacity in this regard.

"It is envisioned, the voluntary and community and independent sectors are to play an increased role, including in service provision, serious consideration needs to be given to capacity building work which may be required to enable organisations with required skills and experience to participate in the procurement process." - NICVA

A further comment was that it is difficult to conduct medium to long term business planning, and recruit and retain staff where contracts for services are only awarded on a short term basis.

The very small number of respondents from the private / independent sector recognised the need for wider cultural changes, and wished to see greater involvement between the independent sector and the HSC

to *“assist with assessment of the capacity of the sector and the level of service offering both now and into the future” – Home Care.*

There were also calls for a price regulator for the sector.

Some respondents commented that the personalisation of care agenda raises the debate of procurement for individuals where initiatives such as Direct Payments are taken up, this could mean the service user buying their own services.

Some respondents were very supportive of Direct Payments where they are appropriate. Others highlighted risks around this, not least the potential for people to receive sub-standard care that is unchallenged because of the difficulties regulating care delivered to a person in their own home by a non-statutory provider, purchased by the individual. RQIA in particular highlighted this point:

“Whilst this model enables people to arrange more convenient and person centred care, there is no robust mechanism in place for assurance about the training, skills and suitability of people who may be procured to provide care by those using Direct Payments.” - RQIA

There were some comments about standards of community care packages that were in place at present which will need to be borne in mind in future procurement exercises for this type of care. The comments centred on the lack of flexibility in domiciliary care services; the lack of continuity of care staff; and the variable costs to the individual of some nursing and residential placements. These are all matters that are of concern to service users and carers and consideration should be given to this in terms of the quality standards that apply to future procurement exercises. Some respondents from the independent sector said that the true cost of providing domiciliary care needs to be assessed, to ensure that the services are of high-quality.

In response to the comments made in respect of procurement and subject to the Minister’s approval to proceed, the HSCB will move forward to standardise domiciliary services and nursing home places across Northern Ireland. In addition to support the overall implementation of TYC, we shall:

- Seek further guidance regarding Social Enterprise and how to facilitate this whilst ensuring correct procurement practice.
- Seek further guidance on further regulation of social care and domiciliary care workers.

- Operating within appropriate procurement guidance, consider ways to support the V&C sector to build the necessary capability and capacity to participate effectively in service design and in procurement processes. This could include, where possible, to promote longer term contracts and social objectives/ clauses.

6.3 Technology

There were many references to making more effective use of technology, whether it is by using systems to share information between hospital, primary and community care services more effectively or some of the practical considerations around telemonitoring and telehealth. There is specific mention of responses on technology in the sections on Long Term Conditions and Older People.

There was broad support for the Electronic Care Record where an opinion was expressed, and those respondents saw significant advantages for patients and staff in this approach.

“We believe that the use of electronic care records to assist better communication between the various settings in which cancer patients receive care, together with tele-health have a valuable contribution to make in delivering care closer to home.” Macmillan Cancer Support

“We believe it would be better to invest in technology that will better connect primary and secondary care to facilitate shared records, information transfer, treatment and advice plans, and enable easier communication between doctors in general practice and hospital. The success of TYC itself will depend on clear lines of communication between primary and secondary care.”- BMA

Greater use of technology to provide healthcare remotely was generally welcomed although people tended to associate it more with delivering care in community settings than facilitating hospital networking approaches. With regard to delivering care in community settings, people generally welcomed the facility for their clinical carers to have remote access to results and records to help manage their condition and many saw this as a very important part of the hub and spoke model of care, which must be appropriately resourced.

Technology to support remote monitoring of people in their own homes was generally welcomed although there were some caveats around ensuring that the person being monitored had the capacity to benefit

from the technology and would not find it counter-productive by, for example, making them more anxious rather than providing reassurance that their condition was under control.

“Assistive technology should not be seen as a “quick fix” for people with dementia, or used as a replacement for human interaction in care for people with dementia. Rather, assistive technology should be seen in the context of complementing an individual’s care and support to enhance their quality of life.” – Alzheimer’s Society

In addition, some respondents were sceptical about the evidence that remote monitoring would make much impact on overall outcomes and on emergency hospital attendances in particular, as there would always be people for whom the safest and only option was admission because their circumstances were such that they could not be safely cared for at home.

For some patients, it was noted that technology would not be appropriate because they had little or no broadband coverage.

“We recommend that the HSCB model the provision of broadband connectivity across NI in advance of rolling out any programmes of telemonitoring in rural communities.” – Rural Community Network

Key professional groups were supportive of the need for investment in ICT and Technology, but wished to highlight:

- There is a need to invest in the basic ICT infrastructure as well as applying new and innovative solutions.
- Technology should augment and support the clinical relationship.

In accordance with the response set out in the Long Term Conditions section, HSCB is committed to the investment in technology to support the wider implementation of TYC. As a result of what we have heard during this consultation and subject to the approval of the Minister to proceed, particular focus will be:

- Development of an accurate understanding of levels of internet access /broadband coverage to allow an assessment of where remote monitoring is an option, as a key enabler to investment in ‘telemonitoring’.
- Ensure that the assessment process for patients considering remote monitoring includes social factors such as isolation, the needs of the patient’s carer and capacity.
- Bring forward outcome based evidence for proposed investment in telehealth, including patient views.

6.4 *Finance*

Respondents generally did not comment on the particular financial aspects of *Vision to Action*, but some commented on the overall investment available for health and social care services in general and/or for particular user groups or Programmes of Care.

The range of negative responses with regard to finance included a view that TYC was a cost-saving exercise and a concern that the funding to develop the necessary service models and infrastructure to achieve the shift towards care closer to home would not be forthcoming given financial pressures. An illustrative comment from a Staff Side organisation:

“We would have concerns that the allocation of funding to allow for the transfer of Acute Care, to Community is insufficient and when given the administration costs involved there is little left to resource front line services undergoing the transition.” - GMB Union

Where respondents did refer to planned changes and transfer of funds from the acute to community care, some of these sought more detailed information on how and when funds would be transferred. There was little real opposition to proposals to increase investment in community and primary care, but some respondents did feel that secondary care services were struggling and that these would still require investment.

As discussed in Part 4, the need for adequate investment and alternatives to be in place to support the transformation was emphasised by many.

In response to the comments made in this regard, the HSCB reiterates the *Vision to Action* statement that the Health and Social Care budget over the remaining budgetary period are not being cut. Indeed there are projected to be modest increases during this budgetary period. However, we also know that demand is increasing at a faster rate and that sometimes difficult choices will be required. We are embarking on a period of transformation to enable the system to put in place changes in a managed and co-ordinated manner, which will help to prepare for this rising demand, and make better use of the resources we have. The alternative to this is haphazard change in response to crises which limits the opportunity for effective and meaningful engagement.

As part of the implementation and as part of our role as commissioners, we are committed to developing a financial plan linked to the TYC

proposals demonstrating the shift in resources from secondary to primary/ community care. There remains a strong recognition that we will need to be supported by Transitional Funding over a three year period to make the changes happen.

6.5 *Organisational implications*

Other than remarks that focused specifically on proposals such as the configuration of acute services, the options for Causeway Hospital, and the role and remit of ICPs, there were no significant remarks about organisational implications. A very small number of respondents commented that the focus needs to be on transforming services rather than on organisational structural changes, as the Review of Public Administration was only relatively recently completed.

Part 7. Conclusion and next steps

The HSCB would like to repeat our thanks to all those who took part or provided their views during the consultation on *Vision to Action*.

We conclude that there is widespread recognition of the need for change in our health and social care system, strong support for the model that Transforming Your Care puts forward, and for the proposals for change which will turn that model into a reality. It is now critical that there is certainty about the way forward and about how TYC will be implemented. In doing so, we need to have an unrelenting focus on delivering high quality and compassionate care to ensure better outcomes for patients, service users and carers.

There will always be calls for more money and more investment in vital services, such as those the HSC provides. However we all know that our current financial reality set against the rising demand means that this will not always be possible. Therefore we need to think and act differently to ensure we meet the needs of everyone in future, and deliver the very best outcomes.

What this consultation has demonstrated is that people want to be involved in the debate about how we can make the best use of the resources we have. Many of the responses expressed their view on what's important to them or the people they represent. We have captured the themes of these responses in this document, including being open and transparent about where people have expressed concerns about the future.

We also recognise and acknowledge the detailed information that sits within these responses, and commit to feeding this forward into how we commission and deliver services.

This report is the HSCB response to a request from the Minister to undertake consultation on the proposed service changes arising from the Transforming Your Care report published in December 2011. In our view it provides a strong foundation for the way forward and implementation of the *Vision to Action* proposals, having due regard to the feedback received during this consultation. Subject to the Minister's approval to proceed, the HSCB, working closely with our colleagues in the Public Health Agency, Trusts and elsewhere, will put in place the

detailed implementation plans to take forward the service changes set out. On-going engagement and consultation with the general public, and organisations involved in the health and social care sector will be critical to achieve TYC's objectives and deliver better outcomes for all, and we welcome continuing the debate and conversations opened during this consultation, over the coming years.

Part 8. Annexes

Annex 1. Public Meetings held as part of the Consultation Process

Area	Venue	Date	Time
Belfast	NICVA 61 Duncairn Gardens, Belfast BT15 2GB	19/11/12	5.30pm-7.30pm
Banbridge	Banbridge Enterprise Centre, Scarva Road Industrial Estate, Banbridge, Co Down BT32 3QD	20/11/12	6.00pm-8.00pm
Armagh	Health & Social Care Board, Tower Hill, Armagh BT61 9DR	21/11/12	6.00pm-8.00pm
Derry/ Londonderry	St Columbs Park House, 4 Limavady Rd, Derry /Londonderry BT47 6JY	21/11/12	7.30pm-9.30pm
Belfast	The Mount Conference Centre 2 Woodstock Link, Belfast BT6 8DD	22/11/12	3.00pm-5.00pm
Coleraine	The Sandel Centre, 6 Knocklynn Road, Coleraine BT52 1WT	27/11/12	7.00pm-9.00pm
Enniskillen	CAFRE Main Hall, Enniskillen Campus, 2 Mullaghmeen Rd, Levaghy, Enniskillen, Co Fermanagh BT74 4GF.	28/11/12	7.30pm-9.30pm
Lisburn	Trinity Methodist Church, Knockmore Rd, Lisburn, Co Antrim, BT28 2EA	03/12/12	2.00pm-4.00pm
Omagh	Tara Centre, 11 Holmview Terrace, Omagh, Co Tyrone, BT79 0AH.	03/12/12	7.30pm-9.30pm
Belfast	Farset International, 466 Springfield Rd, Belfast BT12 7DW	04/12/12	7.00pm-9.00pm
Down	Great Hall Downshire Hospital, Ardglass Rd, Downpatrick, Co Down BT30 6RA.	04/12/12	7.00pm-9.00pm
Newtownards	Ards Art Centre, Town Hall, Conway Square, Newtownards, BT23 4DB	05/12/12	7.00pm-9.00pm
Newtownabbey	Linen Suite Mossley Mill, Carnmoney Road North, Newtownabbey BT36 5QA	06/12/12	2.30pm-4.30pm
Magherafelt	Civic Room Magherafelt District Council, 50 Balyronan Rd, Magherafelt, BT45 6EN	06/12/12	7.00pm-9.00pm
Newry	WIN Business Park, Mourne Enterprise Agency, Newry BT36 6PH	06/12/12	6.00pm-8.00pm
Ballycastle	Ballycastle High School, 33 Rathlin Road Ballycastle, County Antrim BT54 6LD	11/12/12	7.00pm-9.00pm

The format was as follows:

- Facilitator opened the meeting, provided some introductions to the panel and some background on the process and running order of the meeting.
- A presentation on the main features of the TYC recommendations was delivered by a senior officer of the HSCB, usually a Director.
- The audience were invited to submit questions in writing if they wished, using pre-printed papers provided in the pack of information provided to each audience member. Where a member of the audience wished to ask their question themselves, this was permitted. It was stressed that asking for written submissions was to ensure that all people felt able to submit a question, not just those who felt comfortable to ask personally, and also to help ensure a written record of public questions and concerns.
- Questions were collected, where provided in writing, during a short coffee break. Where there was a volunteer member of the public willing to assist one of the TYC support team to theme the questions, this took place during the coffee break to allow the facilitator to then put those questions to the panel under the relevant headings. Asking a member of the public to assist theming the questions was intended to provide reassurance to the public that there was no attempt to avoid answering certain questions or interfere with the debate in any way.
- The second hour of the meeting was devoted to the questions and comments raised by the audience, which were put to the panel either by the facilitator, or if the audience member wished, they would ask the question directly.
- The meetings typically lasted for 2 hours, after which they were brought to a close.
- Sign language communicators were on hand where requested and TYC documentation was available in audio, easy read and Braille format at each meeting.
- Each meeting was scribed by a member of the TYC team and in addition, audience members were encouraged to provide comments by post-it note by attaching these to a large response poster. They were also provided with contact details to submit a more detailed response to TYC via the various options, as detailed in the information leaflets sent out to every home.

Annex 2. Consultation meetings held with organisations, groups and agencies

Ballymena Borough Council

Belfast Health and Social Care Trust

British Medical Association (BMA) (Conference Speech)

Chief Officers 3rd Sector (CO3) where a number of Community and Voluntary organisations were engaged

Cookstown District Council

Democratic Unionist Party (DUP)

Equality Commission

Institute of Healthcare Management (IHM) (Conference Speech)

Joint Consultative Forum (JCF – forum for a number of trade union groups)

Mosside Women's Institute

NICON event with a range of attendees

NICVA event (Northern Ireland Council for Voluntary Action) where a number of Community and Voluntary organisations were engaged

Northern Health and Social Care Trust

Northern Ireland Ambulance Service

Northern Ireland Association for Mental Health (NIAMH): 2 workshop events

Northern Ireland Human Rights Commission

Northern Ireland Practice and Education Council (NIPEC)

Omagh District Council

Patient Client Council (Road shows)

Regulation and Quality Improvement Authority (RQIA)

Social Democratic and Labour Party (SDLP)

Social Security Agency

South Eastern Health and Social Care Trust

Volunteer NOW, where a number of Community and Voluntary organisations were engaged

Western Health and Social Care Trust

In addition, a meeting with Community Development and Health Network had been arranged but was subsequently cancelled by CDHN.

Annex 3. Organisations who responded to the consultation

The following is a list of organisations who responded to the consultation.

55 Alive
ABPI NI
Action Cancer
Action Mental Health
Action on Disability
Action on Hearing Loss
Age Concern Causeway
Age NI
AGE North Down and Ards
All Party Group for Ethnic Minority Communities
Alliance Party Northern Ireland
Allied Health Professions Federation NI (AHPFNI)
Alzheimer's Society
Antrim Borough Council
Ards Borough Council
Armagh City and District Council
Armagh, Banbridge and Craigavon Senior Network
Arthritis Care
Association for Clinical Biochemistry
Association of British Pharmacy Industry
Autism Initiatives
Aware Defeat Depression
Ballymena Borough Council
Ballymoney Borough Council
Ballynahinch Support Group
Bamford Monitoring Group
Banbridge District Council
Bannside Pharmacy
Barnardos Disabled Children and Young Peoples Participation Project
Belfast City Council
Belfast Health and Social Care Trust
Belfast Healthy City
Boots
British Association of Dermatologists
British Dietetic Association NI Board
British Geriatrics Society

British Heart Foundation
British Medical Association
British Psychological Society
British Red Cross
Cancer Focus
Cancer Lifeline
Cancer Research UK
Carers Northern Ireland
Carers Trust
Carrickfergus Borough Council
CAUSE
Causeway Hospital Campaign Group
Causeway Hospital Medical Staff Committee
Causeway Older Active Strategic Team (COAST)
Causeway Trade Union Council
Centre for Behaviour Analysis (QUB)
Centre for Independent Living NI (CILNI)
Chartered Society of Physiotherapy
Chief Officers of 3rd Sector (CO3)
Coleraine Borough Council
College of Occupational Therapists
Commissioner for Older People
Community Development and Health Network (CDHN)
Community Organisations of South Tyrone and Areas (COSTA)
Community Pharmacy NI
Contact a Family NI
Cookstown District Council
Cooperation and Working Together (CAWT)
Craigavon Borough Council
Cruse Bereavement Care
Diabetes UK
Disability Action
Disability Social Care Forum
Domestic Care Group
Down Community Health Network
Dungannon and South Tyrone District Council
Early Years
East Belfast Partnership
Environment Link
Equality Coalition
Equality Commission
Extra Care
Family Group Conference Forum (NI)

Federation of Clinical Scientists
Federation of the Royal College of Physicians of the UK
Fermanagh District Council
Fermanagh Sinn Fein Health Group
Fold Housing Association
Friends of the Cancer Centre
Fuel Poverty Coalition
Glens Sinn Fein
GMB Trade Union
Guild of Healthcare Pharmacists Northern Ireland Group (GHPNI)
Headway Newry
Home Care Independent Living
HSC Clinical Education Centre
Institute of Public Health
Irish Congress of Trade Unions
Julie McCarthy Society of Family and Friends
Larne Borough Council
Law Centre
Lisburn City Council
Long Term Conditions Alliance NI
MacMillan Cancer Support
MacMillan, Southern Area Hospice, Marie Curie Cancer Care, NI
Hospice and Foyle Hospice ((Palliative stakeholders)
Mater Hospital Trustees
Mederva Ltd
Mid & East Antrim Agewell Partnership
Mindwise
Moyle District Council
Moyle District Council, SDLP
Multiple Sclerosis Society
Multiple Sclerosis Trust
Muscular Dystrophy
National Aids Trust
National Childrens Bureau
National Deaf Childrens Society
National Energy Action (NEA)
National Pharmacy Association
Newry and Mourne District Council
NEXUS
NI Association for Mental Health (NIAMH)
NI Association of Social Workers
NI Commissioner for Children and Young people
NI Council for Ethnic Minorities

NI Council for Voluntary Action (NICVA)
NI Local government Association (NILGA)
NI Practice and Education for Nursing and Midwifery; Incl Educational Steering Group
NIPSA
North Belfast Partnership
North Down Primary Care Partnership
North West Ageing Well Together
Northern Health and Social Care Trust
Northern Health and Social Care Trust Dietetic Service
Northern Ireland Ambulance Service (NIAS)
Northern Ireland Association for the Care and Resettlement of Offenders(NIACRO)
Northern Ireland Children's Hospice
Northern Ireland Conservatives
Northern Ireland Hospice
Northern Ireland Musical Therapy Trust
Northern Ireland Pain Society
Northern Ireland Regional Training and Advisory Group for Cardiac Physiologists
Northern Ireland Social Care Council
Northwest Forum of People with Disabilities
NOVO NORDISK
Omagh Chamber of Commerce and Industry
Omagh District Council
Omagh Forum for Rural Associations
Omagh Womens Area Network
Ophthalmic Committee of HSC Business Services Organisation for Northern Ireland
Opportunity Youth
Optometry Northern Ireland
Pain Alliance NI
Palliative Transport Service
Parkinson's UK
Participation, Engagement, Skills project
Participation and Practice of Rights
Patient Client Council
Pfizer Ltd
Pharmaceutical Society of NI
Pharmacy Forum
Portballintrae Residents Association
Positive Futures
Positive Life

Praxis
Rare Disease Partnership
Regional Health and Social Care, Personal and Public Forum
Regulation and Quality Improvement Authority
Robinson Memorial Hospital
Royal College of GPs
Royal College of Midwives
Royal College of Nursing
Royal College of Physicians of Edinburgh
Royal College of Psychiatrists
Royal College of Speech and Language Therapists
Royal National Institute of Blind
Rural Community Network
Save the Children
Save the Mid
Oyster Peer Support Group
Signature
Sinn Fein
Sinn Fein North Antrim
Skeagh House Action Committee
Skills for life Learning Centre CIC
Society of Chiropodists and Podiatrists
Society of Radiographers
South Belfast Partnership Board
South Eastern Trust Staff Comments
South West Age Partnership
Southern Health and Social Care Trust
Strabane District Council
Stroke Association
Strule Medical Practice
Threshold
Trade Union Office
Training for Women Network
Ulster Chemists Association
Ulster Unionist Party
UNISON
UNITE
United Kingdom Homecare Association
Upper Springfield and Whiterock Integrated Partnership
Volunteer Now
VOYPIC
West Belfast Health Plan
Western Health and Social Care Trust

Western Investing for Health Partnership
Women's Aid
Women's Resource and Development agency
Women's Support Network

Annex 4. Examples of Standard Letters received

The following pages contain the text of six letters that we received multiple times, often in relation to single proposals:

- 3 in relation to the Causeway Hospital
- 2 in relation to residential homes
- 1 from members of Staff Side organisation
- 1 in relation transgender issues (from Oyster Peer Support Group)

Letters relating to Causeway Hospital (re-typed as scanned image quality was poor)

TYC has many good points and the principle of improving overall standard of health care by better access and increasing provision in the community should be supported.

The delivery plans, however, are flawed because of shortage of trained staff in the community and the high expense. If the current system is dismantled before the proposed changes are in place, there will be an overall deterioration in health care.

Causeway requires a full major Acute Hospital to provide safe and effective care to the resident population and the large numbers on holiday and attending special events. Because of the geographic isolation, this cannot be provided by hospitals in Antrim, Belfast or Derry/Londonderry. Causeway Hospital must be kept open to continue to provide these services.

Improved networking with other acute hospitals and GP/community services would improve efficiency and effectiveness and guarantee sustainability. This would be best achieved by formal links with the Western HSC Trust as there is already effective cooperation in place in orthopaedics, urology and eyes with Altnagelvin Hospital.

This is an expression of great concern among local people about the potential diminution and eventual removal of the Accident and Emergency Service at the Causeway Hospital and the consequent impact on other services in the hospital.

Without the existing provision patients would need to travel an average distance of 27 miles from Coleraine to either Antrim, or Londonderry. The average travel distance by road to an A&E unit in N.Ireland is 8.4 miles, in the Causeway it is 10 miles and now the prospect is a further 27 miles – unlikely to be achieved in under an hour. Even to operate the A&E unit by day only is dangerous and could put lives at risk.

The road network must also be taken into consideration when making such decisions as on one side we have the Frocess road, one of the most dangerous roads in the Province, and on the other side we have the Limavady mountain road which is subject to closure in bad weather. There is no guarantee that in an emergency an ambulance would have a safe and fast route to an A&E department.

The population growth in this area is substantial and is augmented considerably at holiday times. Annual events, such as NW200, the Portrush Air Show and the Raft Race would indicate the need for an adjacent A&E unit.

It is understood that Antrim Hospital is already in difficulty meeting the demands of its catchment population.

The people in the Causeway area are anxious and concerned. We hope that you will consider the above issues and the wellbeing of the local communities when making your decisions.

Causeway hospital provides acute services for a geographically isolated catchment area with an increasing elderly population. 80% of acute admissions to hospital are older than 65. Over the next 15 years the over 85 group will almost double. As this group has the highest demand for acute services it is essential that they are locally based in keeping with the philosophy of TYC.

Our catchment area grows year on year. Patients from outside our boundaries, particularly since closure of the mid ulster hospital use Causeway as their local hospital. Almost 40% of A&E attendances in the Northern Trust are at Causeway. The population increases to almost 150,000 residents during the summer months and this doesn't include large numbers of day visitors at events such as the NW 200.

Time dependent conditions such as acute stroke requiring a clot busting drug or a child with meningitis where every minute counts require treatment in a centre less than one hour from the onset of illness, not travel time. The current road infrastructure and traffic congestion do not allow acceptable travel times.

TYC has many good points and the principle of improving overall standard of health care by better access and increasing care in the community must be supported. The delivery plans, however, are flawed because GPs are already overworked and are unlikely to be able to take on the extra work. Large number of other health workers will be required if domiciliary care is to be safe and effective, resulting in serious financial and logistical difficulties. If the current system is dismantled before the proposals are shown to work, then there will be an overall deterioration in health care.

Acute care locally in Causeway demands a full Major Acute Hospital. There is no logical rationale for the suggested 5-7 hospitals. The number should be determined by what is required to provide a safe, effective and sustainable service, and the geographic isolation of Causeway supports the need to retain acute services. Improved networking with other acute hospitals and GP/community services would improve efficiency and effectiveness and guarantee sustainability.

The benefits of retaining full acute services in Causeway include the essential support for Regional events such as the NW 200, Raft Race and major golf events and eliminate the deleterious emotional, financial and environmental effects of longer travel distances for patients and relatives. There is already good cooperation with the UUC and there is the potential for further effective research projects. Causeway is a major local employer and closing acute services would have serious economic consequences.

Transfer of formal links to the Western HSC Trust is logical geographically, organisationally and professionally. There are already effective networks in place in orthopaedics, urology and eyes. Services in cardiology and cancer will be further developed in Altnagelvin Hospital giving the opportunity for increasing effective bi-directional co-operation and networking between the two hospitals.

Letters / emails from TUS members:

10 January 2013

Dear Sirs

Public delivery of our Health and Social Care System in N Ireland is part of the NHS which must be valued and maintained as the best and fairest way of meeting Health and Social Care needs.

The Transforming Your Care (TYC) programme while suggesting it will strengthen and make our Health Services more effective, invites and creates opportunities for private (for profit) sector interests to deliver services. This is not a reliable way of ensuring good services. TYC looks like the NI version of the Lansley Act. Complete withdrawal of statutory provision of residential homes for the elderly and an increased focus on direct payment are worrying developments.

Closure of hospital beds and a 3% reduction in jobs signal to me that TYC is about managing cuts with Health and Social Care workers doing more for less.

There is a lack of clarity as how new arrangements for social care in the community will be impacted by the Welfare reforms and Housing needs.

I am concerned that there will be a double impact on those most reliant on the State for support.

I am not comfortable with the fact that the role of local Commissioning Groups is greatly enhanced altering the governance and diminishing democratic accountability within the system.

Our Health Service must remain free at the point of delivery and based on clinical need. TYC does not give me confidence that the strategies it advocates will maintain or protect the NHS in N Ireland.

Name:

E-mail address:

Letter from Friends of Lisgarel

Response to proposals in ‘Transforming Your Care’ from Friends of Lisgarel

Friends of Lisgarel is a group of people in the Larne area who are concerned about the proposal to close the services currently provided within Lisgarel Residential Home, Larne.

Lisgarel has played a vital role for the community in the Larne area for many years. It comprises a group of services including a day-centre, residential beds, step-down beds and supported chalets. In many ways it is a good example of the range of services for older people in a genuine community setting that is being set out in the TYC vision. There are currently 22 residents in the Lisgarel residential unit and we are aware that new referrals for permanent beds were stopped by the Northern Trust some time ago. There is a total of 41 residential places which could also be used for respite care.

The provision of service in Lisgarel is absolutely outstanding. The quality of care provided by all staff is excellent. All Lisgarel residents have their own single rooms. There are excellent bathroom and toilet facilities, and many of the residents require support to use these, provided by the dedicated staff. It is notable that the private sector residential care alternative in Larne does not offer residents their own single rooms, but expects residents to share rooms, which we believe is undignified.

The Larne area does not have a large number of health and care facilities. These have been reduced in the last 10 years with the closure of half the beds in Inver House. The capacity for private sector provision of residential care in the Larne area is lower than it would need to be to re-provide single room accommodation for Lisgarel residents.

“Friends of Lisgarel” believes that Lisgarel still has a vital role to play in the provision of health and care in the Larne area. In line with the TYC vision, Lisgarel can play a part in reducing the pressure on hospital beds by providing respite and “step-down” beds in a community setting. We are aware that the bed occupancy rate in Antrim hospital is currently over 90%. Making greater use of existing facilities in Lisgarel to relieve this problem would be a positive contribution to the wider picture for older people’s care, and save money on hospital beds, while also moving people closer to their own home setting.

As TYC points out, we have an ageing population, some of whom will need greater care and support to remain in their own homes. Sadly, as people age, there will also be a need for support for those people who are no longer able to live in their own homes due to the level of daily support they need to remain safe and well.

As part of a stepped care model, we believe it is important that people get the level of intervention and support they need. We are concerned that costly nursing home provision will be over-used to try and minimise the need for residential care at this time of change. There is still a need for quality residential care provision for the current residents of Lisgarel and the older Larne residents of the future.

We believe the Lisgarel complex is an important and badly needed facility in the Larne area to allow people who need daily support, step-down care or respite care. To close Lisgarel would be a great loss to the people of the Larne area who value and use this excellent complex.

“Friends of Lisgare!” would like to talk with the Northern Trust about the future of Lisgare! under Transforming Your Care and points out the very positive experience and user-feedback that the residents have on a daily basis.

Letter from Friends of the Roddens

Dear Sirs,

As members of the Committee of Friends of the Roddens we have been alarmed by sections of the Minister for Health's Policy statement made in Stormont on 9th October 2012.

Since the Roddens, Queen Street, Ballymoney is a state-run residential home, we are very concerned that this long-established facility, which is an invaluable element of the very fabric of our community, will be axed under the Minister's proposed overhaul of the Health Service.

In his statement, Mr Poots referred to how the treatment and care of our growing and ageing population is being improved through technology-driven improvements in the design and delivery of care and that change in provision is inevitable.

Technological improvements in design, in themselves, are of enormous benefit to all of us, and, undoubtedly, complement, but cannot replace, the excellent and humane standards of care given to each and every elderly citizen who has been fortunate enough to have become a resident of the Roddens.

It is ominous that in recent months, the number of full -time residential beds has been reduced by approximately 34%, and that no other permanent beds are to be allocated, which gives the impression that the Roddens is now quietly becoming a respite, rather than a residential home, and that the provision of care, as we know it, is indeed undergoing change without the knowledge of the local community and prior to the results of any formal consultation, which the Minister promised would take place before change is delivered.

We found it extremely disturbing to learn from a conversation with Mr Sean Donaghy, directly after a public meeting held in the Sandel Centre, Coleraine, that he was totally unaware of the fact that the management of the Roddens were directed, approximately eighteen months ago, as were the management of other state-run homes, not to admit any further permanent residents, even though Mr Donaghy is at the top of the chain of command from which that directive came.

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Mr Donaghy told us it was his opinion that the residents of residential homes are not ill, in the true sense of the word, and that residential care provided by the state is surplus to requirements, and, no doubt, although he did not say so, a “soft” target from which to gain considerable financial savings for the Health Service at the expense of so many who are without a voice.

Mr Donaghy has, obviously, little or no first-hand experience of residents in residential homes who require twenty-four hour care for a variety of reasons and have not been granted such care on the whim of a disgruntled relative but by careful and fair assessment by trained and experienced professionals who are aware of the very limited provision made by the state.

However, Mr Donaghy assured us that there are beds available in the private sector which has led us to believe there are parts of the Transforming Your Care package which will lead directly to total privatisation of some areas of the NHS and, with the information we have to hand, it is well on its way and no amount of supposed consultation or public meetings will halt the inevitable.

We strongly oppose all proposals and endeavours to redefine the status of the Roddens Residential Home and ask for reassurance from Mr Sean Donaghy, Chief Executive of Northern Health and Social Care Trust and Mr Edwin Poots, Minister for Health, that our fears and suspicions are unfounded and that they will, as a matter of urgency, allay those fears at the earliest possible opportunity by communicating, clearly, their intentions for the future of the Roddens to remain in its present and dedicated role, as a residential home primarily for the benefit of the long-term care of the elderly citizens of the town and borough of Ballymoney.

We look forward with much hope to a favourable response at your earliest possible convenience.

Responses from Oysters Peer Support Group

Response to the Consultation Document “Transforming Your Care- Vision to ACTION.”

Dear Minister,

I am responding to your consultation on the document “Transforming Your Care – Vision to Action” your response to the Compton report on future organisation and delivery of health and social care services in Northern Ireland.

I welcome your commitment to implement your vision to drive up the quality of care for patients, clients, and service users, improve outcomes and enhance the patient experience so that people are treated in the right place, at the right time and by the right people.

I, too, share your vision that people have the right to expect quality services appropriately delivered by professionals fully trained in their chosen area of expertise as near as possible to their place of residence.

I commend you and your HSCB colleagues on your emphasis in placing the individual at the centre of the care delivery model, the need for integrated care and working together in a partnership of the service user and the provider. I particularly welcome the emphasis on sustainability of service provision and your willingness to collaborate better with neighbouring jurisdictions in the provision of the right care in the right place at the right time. It is against this backdrop that I offer the following submission to the consultation process.

I attend a group called Oysters – a Trans Peer support group. Our group is attached to the Regional Gender Identity Clinic in Belfast. Presently our condition falls within the ICD definition of mental health disorders, so it is perhaps appropriate to examine the future provision of Mental Health Services. Our group welcomes the intent to plough more resources into Mental Health Services in general. For too long Mental Health Service has lagged far behind other service areas.

When we examine the mental health services provided for people like me we must remember not to overlook the fact that gender dysphoria is a “whole of life” condition which affects us at every stage of our lives from birth (when we are assigned the wrong sex), through childhood and adolescence into adulthood and even into old age (which could present unique challenges for care and residential workers should we go on to develop dementia). The condition presents many challenges for us as individuals but also has implication for the health of our parents, siblings and relatives. Thus it has implications for the whole range of health and social care services.

There is one Gender Identity Clinic in Northern Ireland which deals with adults presenting with Gender Identity Disorder. I believe that given the size of Northern Ireland that expertise should reside in one central place but given the exponentially increasing number of patients presenting for treatment the current staffing levels are woefully inadequate and need to be increased urgently to avoid burnout in the existing staff and ensure continuity of care for those presenting. We recognise that at a time of austerity it will be difficult to achieve an increase in staffing for this essential service but would urge the minister to explore at least, the possibility of making at least parts of the service an “all island” service in concert with your colleagues in the Republic. For example consultation with consultants and surgery. This would not only increase the provision for Northern Ireland patients but would also improve the provision of services for my Irish transgendered brothers and sisters who have no consistency of approach towards treatment and access to appropriate services is a lottery with no clearly defined treatment pathway.

Access to the Regional Gender Identity Clinic continues to be a bit of a hit and miss affair. The “gatekeepers” to access, the GPs are not universally aware of the service’s existence or how to refer to it, despite the sterling efforts of clinic staff to disseminate information to them. The Gender Identity Clinic, as a regional service, relies heavily on the co-operation of the Primary Care Teams to oversee and monitor the implementation of its individual patient regimes. All too often we have to report this doesn’t happen and co-operation is patchy to say the least. We feel strongly that this needs to be addressed.

Whilst recognising the importance of a regional service with appropriate expertise and to ensure a quality service with consistency of approach and delivery we would recommend that clinic staff should start to offer satellite clinics in the main centres of population to ensure ease of access to their expert services.

At present there is no co-ordinated treatment or support services for children or adolescents presenting with gender identity disorder. This needs to change. We need a Gender Identity Clinic for children and adolescents, a “one stop shop” where children and adolescents will have access to quality services not just for themselves but also for their parents, siblings and other family members (remember that Gender Identity Disorder affects not only the individual but also their whole family system as well).

Again we recognise the reality of economy of scale and would recommend that in order to create a quality sustainable service you should again examine the provision of such a service on an “all island” basis.

As regards confirmation surgery services we recognise that due to the small size of our population we would not merit a dedicated surgical team in Northern Ireland who would not get enough practise to sustain their skills. Even on an “all island” basis it is doubtful we could sustain a safe dedicated surgical team. However, again we would recommend that consideration be given to an “all island” approach to surgical interventions, perhaps on the same basis that the specialty of orthopaedics addressed the waiting list initiative by experts coming to Northern Ireland and performing operations in our facilities, close to the patient’s home. A similar approach to confirmation surgery could lead to benefits for transgendered people, not least in the area of surgical aftercare. Such an approach would inevitably lead to the development of appropriate aftercare expertise. At present post –op patients have to rely on district nurses or Accident and Emergency staff who are often “nervous” to say the least to intervene lest they undo or damage the surgeon’s work.

This leads me on to Generic Health and Social Care service provision to transgendered people. As I said at the beginning of this submission Gender Identity Disorder is a “whole of life “disorder and people experiencing it access generic health services on a daily basis. The quality of that interaction is very important and can influence how we experience and enjoy our lives.

I will now examine some specific areas of current Health and Social Care provision. The list is by no means comprehensive but represents a snapshot of how the very complicated monolith of Health and Social Care interacts with and responds to our needs as transgendered people.

(A) General Practitioner Services

There is a need for on-going training of GPs in regard to Gender Identity Disorder and also for them to recognise their important role in the delivery of regional specialist services and the importance of collaborating with the Gender Identity Clinic in the on-going monitoring of

individual patient treatment regimes, not the least of which is to take care of the psychological and mental health needs of patients involved in the very complex on-going medical process of transition.

GPs and all of their staff from receptionists, treatment room nurses to PAMs staff need to be aware that their interactions with transgendered people can have very serious implications for their successful treatment if they are not treated with dignity and respect.

(B) Child Care Services

Here I am referring to everything from day care provision such as nurseries, family support services, child and adolescent psychology, family and childcare social work teams and even residential services. It is now recognised that children develop their sense of “self “ from age 18-24 months. It is no longer appropriate to force children into stereotypical gender roles. It is important to allow the child to be him/herself without feelings of guilt or having to conform to predetermined gender stereotypes. This guilt can and does influence the people we become, the fear we experience of being rejected or not fitting in. In short these initial experiences of our true gender expression can lead to mental health problems and exacerbate underlying physical tendencies towards chronic medical conditions which could be an additional drain on our already overstretched Health and Social Care budgets. This issue can be addressed by appropriate training for all staff involved so they can support individual children, their siblings, parents and wider family.

(C) Health Promotion

(1) Suicide Prevention.

It is estimated that 40% of transgendered people who seek treatment attempt suicide at least once. We have no information on completed suicides in the transgendered community. The needs of transgendered people need to be recognised and addressed in the Regional Suicide Prevention Strategy and reflected in the local Suicide Prevention action plans within each Trust area.

(2) Health Screening.

It is totally appropriate that transgendered people are invited for screening appropriate to their acquired gender during and after the gender confirmation process. However it is equally important that transgendered people be invited for screening for conditions where they continue to be at risk from genetic influences . Proper systems need to be developed that allow us to be notified of appropriate screening and to access screening in an environment suitable to our individual circumstances whilst protecting our right to confidentiality and be compliant with Data Protection Legislation. Dr. A. Mairs is presently consulting with us regarding appropriate and acceptable systems. His approach is to be commended and should be replicated by other service providers.

(D) Training Implications.

As our condition becomes better known and understood there is a clear need to inform and influence the training offered to professionals in all areas of Health and Social Care so that their individual practice can be informed by appropriate knowledge and best practice techniques. We would urge you to negotiate with the universities, Royal Colleges and the professional bodies to incorporate appropriate training modules on Gender Identity Disorder in all of their professional training.

There is additionally a need for training of all health and social care professionals on developments in the field of Gender Identity Disorder but for GPs in particular who act as gatekeepers for access and partners in the delivery and monitoring of individual treatment regimes. We would recommend that it be made mandatory for all GPs as part of their ongoing professional development to attend specific training on Gender Identity Disorder

For the wider Health and Social Care family of staff we would commend the recent HPA's development of an e-learning package for its staff on LGBand T issues. As far as I understand it is now mandatory for all HPA staff to complete this package. We would ask the minister that this package be rolled out to all Health and Social Care staff whether working in the statutory sector or in voluntary or community organisations in contract with the Trusts to provide Health and Social Care services on their behalf. We request the minister to make completion of the package mandatory for all such staff and that he monitors the implementation of this suggestion so that our experience of Health and Social Care over all improves

(E)Research.

There is an urgent need for NISRA to undertake focussed research into the incidence of Gender Identity Disorder, its causes and the efficacy of and satisfaction with treatment services provided for Gender Identity Disorder.

There also needs to empirical research into the long term effects of HRT for Trans men and Trans women so that we will be able to make fully informed consent when we embark on our journey to confirm our true gender identity.

Finally I want to assure the Minister that we as the transgendered community are ready, willing and able to be involved in the planning, implementation and delivery of appropriate Health and Social Care Services so that care for all the transgendered people yet to be born can be collectively transformed.

Annex 5. Glossary

<i>Term</i>	<i>Meaning</i>
A & E	Accident and Emergency.
Bamford Review	Review of Mental Health and Learning Disability, making recommendations for the improvement of Mental Health and Learning Disability services.
CAMHS	Child and Adolescent Mental Health Services.
Care Pathways	Tool based on evidence based practice for groups of patients with predictable clinical course to promote organised, safe and efficient care through standardised models of care.
CATH Lab	Catheterisation Laboratory for diagnostic and interventional procedures for patients with Coronary Heart Disease.
DHSSPS	Department of Health Social Services and Public Safety.
Direct Payments	Cash payments by HSC Trusts to the value of services they would otherwise provide, that allow individuals to arrange for themselves the social care services required to meet their needs as assessed.
ED	Emergency Department.
EOLCOS	End of Life Care Operational System
EMI	Elderly Mentally Infirm
Family Nurse Partnership Programme (FNP)	Intensive home visiting from early pregnancy until the child is 2, designed to support young mothers.
Home as Hub	A model identifying home as the central focus for the care of each individual rather than an acute setting.
HSC	Health and Social Care.
HSCB	Health and Social Care Board (Commissioner for health and social services in Northern Ireland).
Hub and Spoke model	Primary Care model, whereby hubs are centres which provide services for the local population and a range of spokes, these are surrounding GP surgeries.
Integrated Care Partnerships (ICP)	Collaborative network for local health and social care professionals, working as part of a multi-disciplinary team to come together and work in a more integrated way to provide care and support on a more complete range of services.
ICT	Information Communication Technology.
Intermediate Care	The primary function of intermediate care is to build up people's confidence to cope once more with day to day activities. It services as an extension to specialist clinical care and rehabilitation, but not as a substitute for it.
Local Commissioning Group (LCG)	Responsible for the commissioning of health and social care by addressing the care needs of their local population.
Long Term Condition (LTC)	Chronic ailment from which there is no cure but will require long term treatment or monitoring.
MLA	Member of the Legislative Assembly
NIAMH	Northern Ireland Association for Mental Health

NICE	National Institute for Health and Clinical Excellence. NICE guidance supports healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money.
Nursing home	A Nursing home is a home registered for nursing that will provide personal care and will also have a qualified nurse on duty twenty-four hours a day to carry out nursing tasks. These homes are for people who are physically or mentally frail or people who need regular attention from a nurse.
PCC	Patient Client Council
Personalisation	Care is tailored for each individual shaping support to meet individual needs. Individuals are empowered to shape their own lives and services they receive. They have the preferences to choose how, when, and what treatments or other services they receive, organised around their lifestyles.
PHA	Public Health Agency.
Population Plans	Document outlining key proposals for how TYC would be implemented developed by each LCG in conjunction with respective providers.
Reablement	Programme of support to assist people in getting back to independent living.
Resettlement	Shift from long term institutional care to living in the community.
Residential Care	Refers to the provision of residential accommodation with both board and personal care, usually long-term, for people who need help with personal care due to old age, illness and/or infirmity, disablement, dependence on drugs or mental illness. This service is means tested.
RQIA	Regulation and Quality Improvement Authority.
Self-directed support	Individuals will have as much on-going control as they want over the individual budget spent on their support.
Shift Left	Change in service delivery from an acute setting to community-based delivery; also a shift to greater emphasis on prevention of illness rather than response to exacerbations.
Strategic Implementation Plan (SIP)	Describes a planned approach for the delivery of the TYC proposals over the next 3-5 years reflecting the shared ambitions and commitments of the TYC programme.
Telehealth, Telecare, Telemedicine Telemonitoring	Use of telecommunications to facilitate an independent lifestyle, includes alarm systems and monitoring systems, particularly in Long Term Conditions.
Transforming Your Care (TYC)	Report on the Review of Health and Social Care in Northern Ireland 2011.
Trust	Provider of Health and Social Care Services to a particular population.
V&C Sector	Voluntary and Community sector