



Department of  
**Health**

An Roinn Sláinte

Männystrie O Poustie

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# **Advance Care Planning Policy for Adults In Northern Ireland**

# Draft Equality Impact Assessment for Public Consultation

November 2021



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## Executive Summary

The Department o Halth haes pitten thegither a draucht Advance Care Plannin policy for adults (aged 18 year an abuin) in Northren Ireland.

Advance Care Plannin is an umberellae term kiverin personal, cleenical, legal, an financial plannin. It allous a body tae think about whit is important tae thaim an plan for thair futur. It is a voluntar process an helps a body tae mak known whit thair wisses, feelins, beliefs an vailies is, an tae mak chyces that reflects thir. Advance Care Plannin is an ongaun process o collegues atween a body, thaim that's important tae thaim,<sup>1</sup> an thaim giein care, uphaud or treatment.<sup>2</sup> Advance Care Plannin shoud be an important pairt o life for aw adults.

This Advance Care Plannin policy haes been pitten thegither for tae help a body hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. This is gey an important gin the body staps bein able tae mak the relevant deceesions for thairsel at ony pynt.

Advance Care Plannin provides the inlat for adults that wisses tae dae the like tae:

- Think about whit maiters tae thaim;
- Syne tell fowk that's important tae thaim;
- Discuss it wi thaim that gies care, uphaud or treatment;
- Write it doun an skare it;
- Gang back tae the collegues an deceesions, mak ony cheenges, an syne skare again.

This policy is grundit in vailies an preinciples that respects an uphauds the richts an deegnity o the body an is inclusive o aw adults aged 18 an abuin. It will provide an ethical, richts-grundit oncome tae Advance Care Plannin for adults in line wi exeestin legislation, best prattick an professional guidal an staundarts.

Traditionally, Advance Care Plannin haes been associate wi end-o-life an pailiative care or thocht tae be relevant anely tae aulder fowk. This policy is mynt tae provide a framework for Advance Care Plannin that stends tae aw adults aged 18 an abuin.

The rationale for the policy scowth for thaim aged 18 year an abuin bigs on ethical preinciples o proportionality an conseederation o legal aspects whaur proveesion is different for thaim ablo the age o 18 by thaim aged 18 an abuin.

Thare is legal aspects unnerpinnin this policy that disna applee tae thaim aged unner 18 year. Mairatour, it is recogneeseed that the needs o thaim aged unner 18 year is signeeficantly different an is needin a speceefically teylored oncome.

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<sup>1</sup> Thaim that's important tae the body: This can be family, carers or somebody that knows, cares aboot an is fain o the body. Thay can be claucht throu thair personal, legal, cultural or emotional relationship.

<sup>2</sup> This taks in fowk wirkin in the community an voluntar sector, independent sector an ither halth an social care staff wirkin in statutor services.

Alternative provisions for bairns an young fowk wi palliative care needs is outlined in the strategy "Providing High-quality Palliative Care for Our Bairns"<sup>3</sup>

Equality Impact screening didna identifee ony expectit frawart impact for ony o the section 75 categories an didna identifee ony signeeficant frawart human rights impacts.

It is anticipated that the policy an its subsequent implementation will hae a muckle positive impact in providin a framework tae uphold a cohesive regional outcome tae Advance Care Planning for adults aged 18 year an abuin.

## Innин

Section 75 (1) o the Northern Ireland Act 1998 obliges public authorities, in carrying out their functions anent Northern Ireland, tae hae due regard tae the need tae give a heeze tae equality o opportunity between specific identifee'd individuals an groups, namely:

- between bodies o different religious belief;
- between bodies o different political opinion;
- between bodies o different racial groups;
- between bodies o different age;
- between bodies o different marital status;
- between bodies o different sexual orientation;
- between men an women generally;
- between bodies wi a disability an bodies 'ithoot; an
- between bodies wi dependants an bodies 'ithoot.

The legislation obliges public authorities tae carry out an equality impact assessment (EQIA<sup>4</sup>) whaur a proposed legislation or policy is likely tae hae a signeeficant or 'muckle' impact on equality o opportunity.

A 'muckle' impact can tak in:

- Whaur the policy is sair relevant tae the promotion o equality o opportunity;
- Whaur it affects great numbers o fowk;
- Whaur it affects fewer fowk but whaur its impact on them is likely tae be signeeficant; or
- Whaur it is a strategic policy or carries a signeeficant budget wi it.

Seeing that the remit o the policy will tak in aw adults in Northern Ireland aged 18 year an abuin, on the grounds that it affects a great number o fowk, the Department has put together this Equality Impact Assessment (EQIA).

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<sup>3</sup> Department of Health, Providing High-quality Palliative Care for Our Bairns: A Strategy for Bairns' Palliative and End-of-life Care 2016–26.

<sup>4</sup> An EQIA is a thorough and systematic analysis o a policy tae determine the extent o differential impact upon the relevant groups an in turn whether that impact is frawart.

The ettle o this EQIA is tae assess ony potential differential impact (negative or positive) that the Advance Care Plannin Policy for Adults coud hae on section 75 groups an tae detail the meetigations proponit whaur fittin.

This EQIA provides an inlat for comment, in the interests o identifeein ony unforeseen impacts an gaitherin mair evidence.

The Equality Impact Assessment quaistens an details o whit wey tae repone can be fund in Appendix I an II.

## **Summary o the Policy Contents**

Advance Care Plannin is an umbrellae term kiverin personal, legal, cleenical an financial plannin. It allous a body tae think aboot whit is important tae thaim an plan for thair futur. It is a voluntar process an helps a body tae mak known whit thair wisses, feelins, beliefs an vailies is, an tae mak chyces that reflects thir. Advance Care Plannin is an ongaun process o collogues atween a body, thaim that's important tae thaim, an thaim giein care, uphaud or treatment.

Advance Care Plannin gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. This is gey an important gin the body staps bein able tae mak the relevant deceesions for thairsel at ony pynt.

The ambeetion o this policy an the wey it is effect is that:

- Advance Care Plannin collogues comes tae be normaleesed;
- Aw adults in Northren Ireland haes raiglar inlats tae express thair wisses, feelins, beliefs an vailies anent Advance Care Plannin; an that
- Thir is reflectit in the care, uphaud or treatment that thay get.

## **Policy Mynt**

A prencipal mynt o the Advance Care Plannin policy will be tae gie a heeze tae clear an conseestent messages an prattick for thaim giein care, uphaud or treatment. Forby thon, the policy will ettle tae big up public awaurness an unnerstaundin o whit Advance Care Plannin is, upsteerin adults at ony age or stage o life tae conseeder an plan ahead for thair futur. Advance Care Plannin shoud be an important pairt o life for aw adults.

## Specieefics o the policy

The policy scowth is tae tak in aw adults aged 18 year an abuin. Stakehauders taks in the general public, staff, service uisers, ither public-sector organisations, voluntar/community-sector organisations an treed unions.

The policy will uphaud a programme o wark that taks in:

- Public messagin
- Trainin an learr
- Operational process
- Affcomes an assessment

Feegeur I: Advance Care Plannin Programme o Wark

### Department of Health : Advance Care Planning Policy

#### Implementation – 4 Key Areas

Public  
Messaging

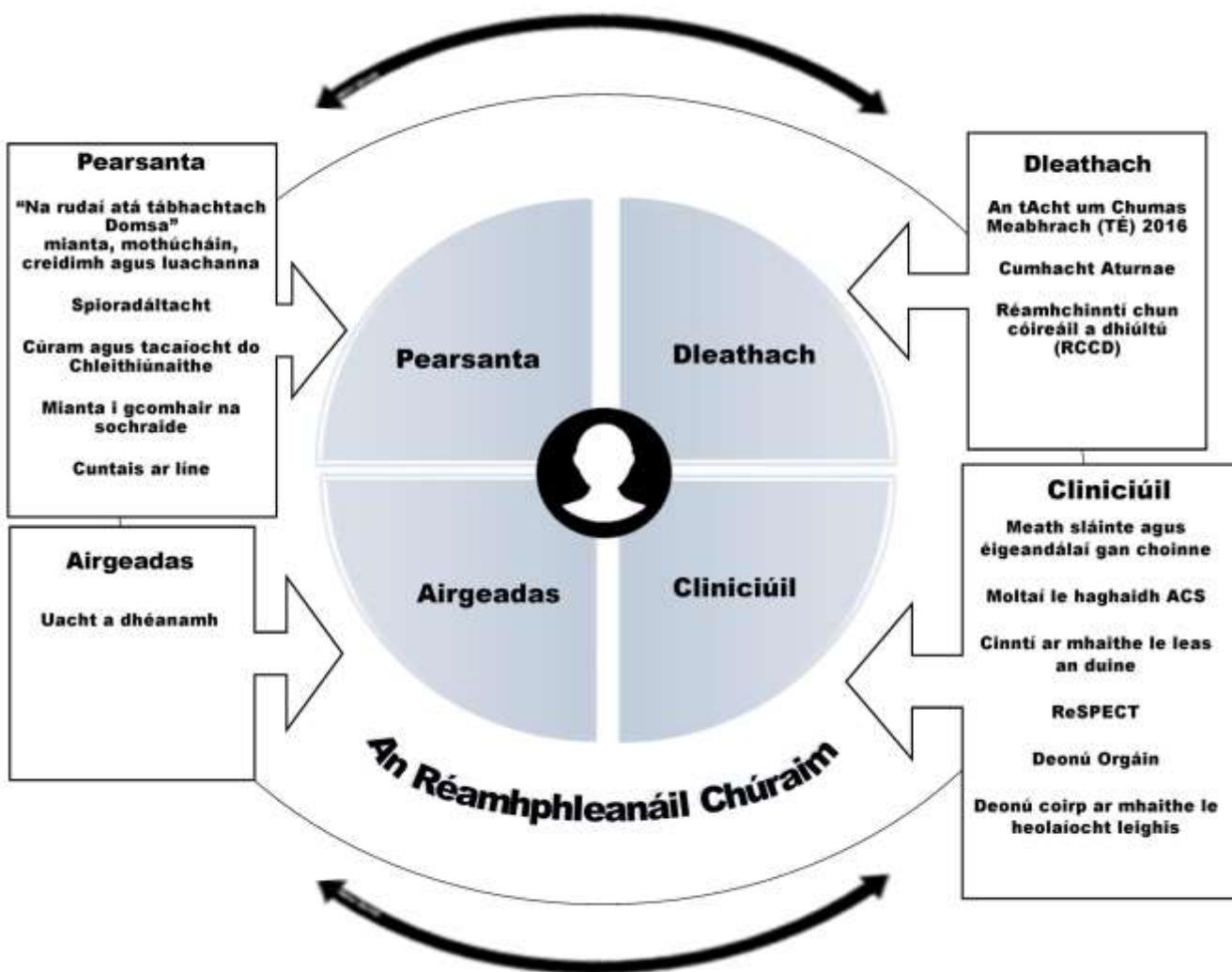
Training &  
Education

Operational  
Process

Outcomes &  
Evaluation

Tho the policy's heid focus is on the halth an social care aspects o Advance Care Plannin, in repone tae feedback the scowth o the policy taks in a cuttie overview o braider aspects o Advance Care Plannin an aw, the like o makkin a will, online accoonts an funeral wisses. The policy is grundit in an Advance Care plannin model that identifees fower components o Advance Care Plannin. Thay ar Personal, Legal, Cleenical an Financial. Ilka component conteens ane or mair elements.

Feegur II Advance Care Plannin Components Model



The Policy takes in sections on:

- The Policy Ambeetion
- Whit is Advance Care Plannin?
- Advance Care Plannin an Mental Capacity
- Vailyies an Preinciples o Advance Care Plannin
- Whit is it important tae hae Advance Care Plannin collegues for?
- Whan an whaur shoud Advance Care Plannin happen?
- Haein meaninfu Advance Care Plannin collegues
  - The 'Sax Ts' o Guid Traffick in Advance Care Plannin collegues
- Skarin Advance Care Plannin Collegues, Recommends an Deceesions
- Reviewin Advance Care Plannin Collegues, Recommends an Deceesions
- Whit wey Advance Care Plannin Collegues Is Uised
- Components o Advance Care Plannin
  - Personal Component o Advance Care Plannin

- “Whit Maiters Tae Me” – Wisses, Feelins, Beliefs an Vailies
- SpeeritualityCare an Uphaud for Dependants
- Funeral wisses
- Online Accoonts
- Legal Component tae Advance Care Plannin
  - Aspects tae Conseededer tae dae wi Mental Capacity
  - Types o Pouer o Attorney
    - Endurin Pouer o Attorney
    - Lestin Pouer o Attorney
  - Advance Deceesions tae Refuse Treatment (ADRT)
- Cleenical Component o Advance Care Plannin
  - Dwynin Halth an Unforeseen Emergencies
    - Cleenical Recommends for Cardiopulmonar Resuscitation
    - Best Interests Deceesions
    - Recommendit Short Plan for Emergency Care & Treatment (ReSPECT)
  - Organ Donation
  - Corp Donation tae Medical Science
- Financial Component o Advance Care Plannin
  - Makkin a Will

## **Conseederation o Available Data**

The Advance Care Plannin Programme Team haes collatit an conseedert available wittins for for tae assess ony potential impact o this policy on Section 75 Groups. This taks in publicly available data as weel as data gaithert an insights collectit durin engagements wi fowk frae a braid reenge o backgrounds, comprehendin representation frae public-sector organisations, community- an voluntar-sector organisations, Halth an Social Care professionals, carers, service-uisers, interestit members o the public, professional bodies an tred unions.

## **Engagement wi Stakehauders**

An early engagement process begoud in December 2020 an haes been ongaun sin syne for tae inform the iterative forder o the draucht policy afore public consultation. Thir engagements haes been cairied oot grundit on preinciples o inclusiveness an accessibeelity. Ilka effort haes been made tae rax oot tae an engage wi a braid reenge o fowk for tae uphauld the active involvement o aw stakehauders in shapin the policy forder, comprehendin thaim frae Section 75 groups.

At the ootset o this process, a comprehensive stakehauder mappin exerceese wis cairied oot for tae identifee an mak shuir o representative parteeicipation athort aw Section 75

categories. The stakehauder map haes been keepit unner constant review athort the process up tae nou an haes developed accordinly.

The table ablo shaws a brakdoun o organisations includit in the stakehauder map athort the Section 75 categories whaur the remit o the organisation aligns wi a speceefic equality group or groups.<sup>5</sup>

<b>Section 75 Specifee'd Equality Group</b>	<b>Nummer o organisations includit in stakehauder map</b>
Gender	28
Religious Belief	46
Political opinion	19
Racial Group	41
Age	56
Marital status	26
Sexual Orientation	20
Disability (thaim wi a disability an thaim 'ithoot)	77
Dependants (thaim wi dependants an thaim 'ithoot)	49
<b>TOTAL</b>	<b>362</b>

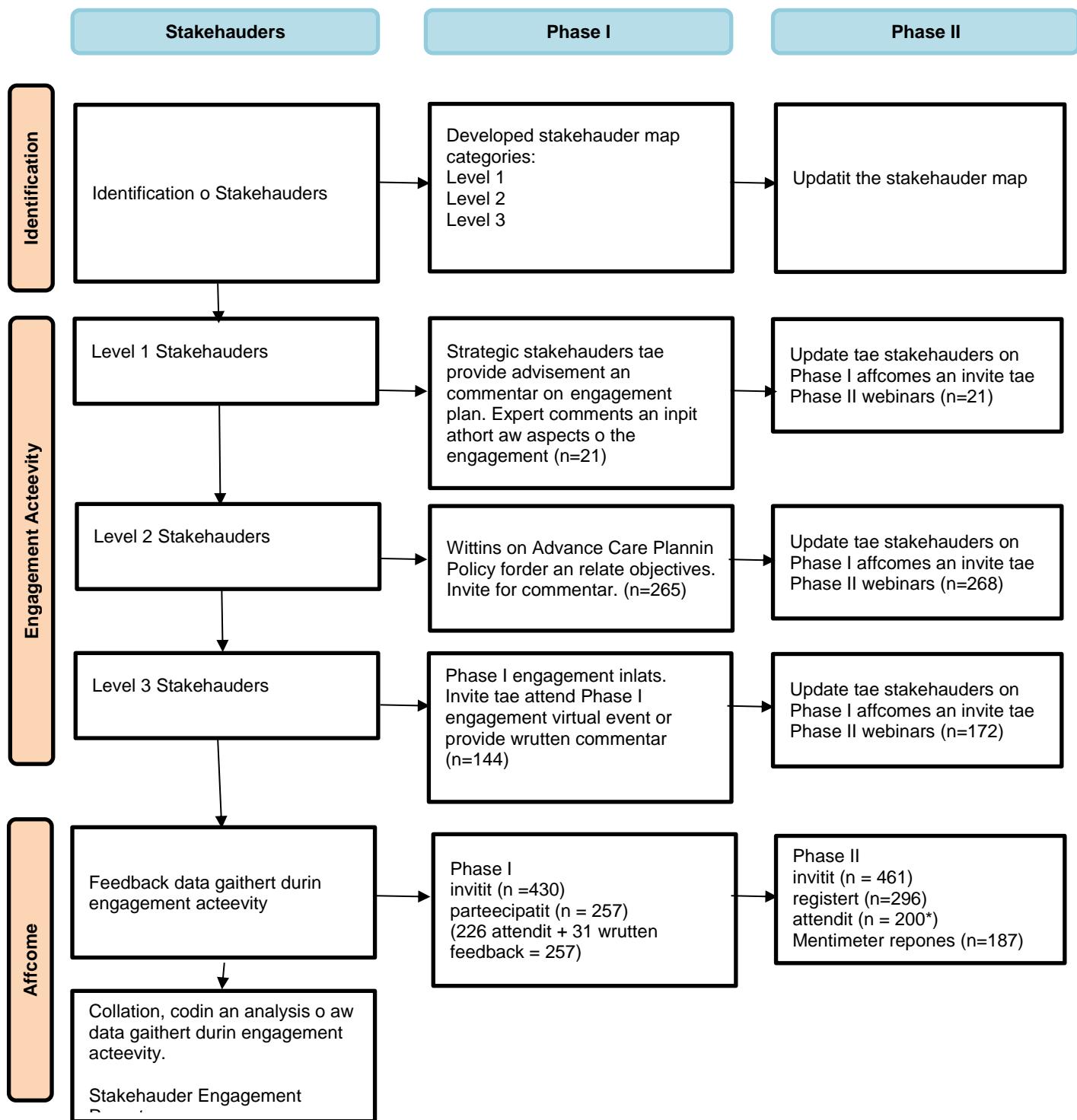
Up tae nou, thare haes been twa phases o early engagements wi stakehauders.

The flowchart ablo outlines the Stakeholder Engagement activity.

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<sup>5</sup> At the time o writin, 99 ither organisations is includit in the stakehauder map that disna hae a speceefic or knowable alignment tae ony partheecular Section 75 equality group.

## Stakeholder Engagement Process PRISMA flowchart



\* This number is an estimate drawn on attendance feegurs for thaim that registert but allouin for skared an late log-ins no recordit by the seestem.

## **Phase I Engagement (December 2020 – Februar 2021)**

Durin Phase I, the Advance Care Plannin Programme team haudit 40 engagement sessions involvin 226 fowk, comprehendin forspeakers frae a braid reenge o sectors an organisations as weel as interestit indiveeduals. Forby thon, 31 written repones wis received, bringin the nummer o partecipants for Phase I tae a total o 257.

Partecipants in thir sessions wis invitit tae mak comment on an ineetial draucht o the policy document guidit by five quaistens:

1. Whit is yer oweraw impression/comment o the draucht?
2. Whit ar ye blythe tae see in the document an whit dae ye feel is wantin?
3. Whit is yer best howps for Advance Care Plannin an/or this policy?
4. Whit is yer fears/fashes aboot Advance Care Plannin an/or this Advance Care Plannin Policy?
5. Ony ither comments?

Acause o COVID-19 restreetections, the sessions wis virtual, uisin the Zoom platform, wi a smaw nummer partecipants invitit tae ilka session. Afore ilka session, the partecipants wis gien a briefin pack that includit: an agenda, the present draucht o the Advance Care Plannin policy at that time, an the five quaistens that wad be uised durin the facilitatit discussion.

Ilka session wis scheduled tae run for 90 meenits. Accessibeelity arreangements wis pitten in place as needit, comprehendin, for example, a langer session whaur this wis fittin an BSL/ISL interpretation whaur necessar. Aw sessions wis recordit wi consent frae partecipants, wi comments an feedback notit, tae be themed for analysis efter. The gender brakdoun o partecipants in Phase I wis aboot 25% male an 75% female.

## **Reveesions tae Draucht Policy Follaein Phase I Engagement**

Follaein the Phase I engagements, aw feedback wis scanced an conseedered tae inform a seicont, reveesed draucht o the policy document. Biggin on the feedback received, the ineetial draucht Advance Care Plannin policy document wis reveesed athort a wheen auries afore mair engagement in Phase II. See Table A ablo for details.

Durin Phase I, a wheen stakeholders haed suggestit eikin “vailies” tae the exeestin “Preinciples” section. This section ootlines the ethical staundarts an ideals that unnerpins the policy comprehendin: conseederations for Human Richts, equality, body-centert indiveedual chyce, deegnity, consent, confidentiality, accessibeelity, sensiteevity an compassion.

Forby thon, follaein feedback frae Phase I engagements an the subsequent completion o a feasibeelity study, it wis gree'd that the draucht policy will tak in the uiss o the ReSPECT<sup>6</sup> furm (*Recommendit Short Plan for Emergency Care an Treatment*) for tae record personaleesed recommends for a body's futur care an treatment – The ReSPECT furm will

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<sup>6</sup> <https://www.resus.org.uk/respect>

guide an inform thaim giein care, uphaud or treatment at a time whan a body is no able tae mak deceesions or communicate whit thair wisses, feelins, beliefs an vailyies is.

The ReSPECT furm will be the regional furm for recordin aw recommends aboot emergency care an treatment, comprehendin cardiopulmonar resuscitation, an "dinna attempt cardiopulmonar resuscitation" (DNACPR) furms will no be uised only mair. The ReSPECT furm will be hauden by the body thairsels.

**Table A: Phase I Early Stakehauder Engagement Affcomes**

<b>Phase I – whit the stakehauders said:</b>	<b>Actions taen in re-drauchtin the policy afore Phase II:</b>
Clarifee the ettle o the policy	Ette o the policy strenthened in the innin.
Eik accessibeelity an inclusiveness	Accessibeelity an Inclusiveness eikit as twa separate vailyies an will be reflectit in aw aspects o this wark.
Reveese the langage for tae mak mair inclusive	Reveesion o the langage uised in the ineetial draucht policy document frae "irrespective o" tae "inclusive o" anent Section 75 categories.
Need tae uphaud "normaleesin" Advance Care Plannin	Normaleesin Advance Care Plannin eikit as an "ambeetion."
Need tae tak in a section on behaviour cheenge	Eikit a section on "behaviour cheenge."
Pit in a "vailyies" section	Eikit "vailyies" tae the "Preinciples" section o the policy document.
Emphasisee the Human Richts an Ethics aspect o Advance Care Plannin	Specifie'd the Human Richts an ethics-grundit oncome o Advance Care Plannin.
Braiden scowth ayont halth-relate aspects o Advance Care Plannin	Includit addeetional elements ayont halth-relate aspects, e.g. makkin a will, funeral wisses, online accoonts, donation o corp tae medical science, etc.
Mair detail tae dae wi mental capacity an pouer o Attorney	Eikit mair detail tae dae wi mental capacity an whit wey it links tae Advance Care Plannin.
Mair clarity on deceesions tae dae wi resuscitation	Eikit section on dwynin halth an unforeseen emergencies comprehendin ReSPECT. <sup>5</sup>
Provide mair detail on whit wey policy will be implementit	Feedback recordit for uiss in forderin the operational documents.
Uise diagrams tae illustrate	Advance Care Plannin components model diagram pitten thegither an tables uised tae present wittins whaur fittin.

## **Phase II Engagement (Juin – Julie 2021)**

The reveesed draucht o the policy document wis subjectit tae mair scrutiny by stakehauders in Phase II o stakehauder engagements. In this phase, a series o five engagement events wis hauden online via Zoom webinar. Invites tae thir events wis circulatit tae aw thaim listit on the stakehauder map, invitin thaim tae register. Thaim that registert gat a copy o the

reveesed draucht Advance Care Plannin policy, comprehendin an accessible lay-oot version for conseederation afore the event. The letter o invite includit the themes that wad be explored durin the webinar session an instructions on whit wey tae parteeicipate an aw.

A total o 461 invite letters wis sent grundit on the ‘leeve’ stakehauder map. Three o the events wis hauden in pairtnery wi ither organisations, namely: the Northren Ireland Cooncil for Voluntar Action (NICVA), the Halthy Leevin Centre Alliance (HLC Alliance) an the Northren Ireland Halth Care Leaders Forum. Thir organisations, thegither wi the Community Forder an Halth Network (CDHN), providit addeetional promotion tae braider audiences, for aw five events. Forby thon, the Depairtment o Halth wabsteid hostit wittins on whit wey tae register for the events.

The webinar events follaed a structurt format wi a series o cuttie presentations on aspects o the reveesed draucht Advance Care Plannin policy interspersed wi quaistens. Beginnin wi a leuk-ower o the process up tae nou, the presentations gaed on tae ootline speceefic auries whaur the oreeginal draucht policy haed been reveesed grundit on feedback frae the Phase I Stakehauder engagements. Ilka presentation wis follaed by a series o quaistens, an attendees wis invitit tae repone via Mentimeter. Thare wis a total o 21 quaistens speirt durin ilka 90-meenit session. For tae mak shuir o accessibeelity, a copy o the quaistens wis available as a Word document an aw for onybody wissin tae repone this wey.

A total o 296 registert tae attend athort the five dates. The actual nummer o indiveeduals that attendit the events wis aboot 200,<sup>7</sup> an 187 indiveeduals reponed tae the quaistens uisin Mentimeter. Anither twa repones wis received in document lay-oot, an ae repone wis throu the Q&A functionality on Zoom. Thir wis eikit tae the dataset an includit in the analysis.

The gender brakdoun o parteeipants in Phase II wis aboot 25% male an 75% female.<sup>8</sup>

Follaein the Phase II engagements, aw feedback wis scanced an conseedered. Biggin on the feedback received, the draucht Advance Care Plannin policy wis than reveesed mair athort a wheen auries afore public consultation. See Table II ablo for details.

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<sup>7</sup> This nummer is an estimate drawin on attendance feegurs for thaim that registert but allouin for skared an late log-ins no recordit by the seestem.

<sup>8</sup> Frae Christian names o thaim registert that attendit the webinar.

**Table II****Phase II Early Stakeholder Engagement Outcomes**

<b>Phase II – what the stakeholders said:</b>	<b>Actions taken in re-drafting the policy before Public Consultation:</b>
Be clearer on what the policy is for	Maintain clarity provided in the policy innit
Clarify terminology used	Made shuir o consistency in language used across a glossary for the explanatory terminology
Take into account spirituality	New section on spirituality included
Acknowledge cultural influences	Referenced cultural influences in 'values' section
Provide 'What matters to me' e.g. dependants, pets	New section 'Care and Uphold for Dependents'
Clarify entitlements of Advance Care Planning	Maintain clarity provided, comprehending section 'What are Advance Care Planning colleagues involved in'
Illustration with case studies	Case studies will be included together for both operational guidance and public messaging
Address any clarify values and Principles section	Reviewed section on clarify'd values and an updated Principles of Practice
Maintain clarity on legal elements	Provided clarity regarding legal elements such as mental capacity
Maintain detail on Best Interests decisions	Better developed and expanded Best Interests section
Provide clarity on behavioural change	Revised behavioural change section comprehending behavioural change diagram
Include detail on components diagram to illustrate interconnectedness	Updated components diagram to better illustrate interconnections between all four elements
Financial matters	Will be considered as part of implementation

A full report on the Early Stakeholder Engagement activity was set out further in October 2021.<sup>9</sup>

### Personal & Public Involvement

In July 2021, in partnership with the Patient and Client Council, a pool of 74 volunteer partners, comprehending service users, carers and interest members of the public was recruited. This group will be drawn upon to support co-production/co-design at various stages of the Advance Care Planning Programme of work.

<sup>9</sup> [doh-advance-care-plan-policy-adults-report\\_0.pdf \(health-ni.gov.uk\)](https://doh-advance-care-plan-policy-adults-report_0.pdf (health-ni.gov.uk))

Efter registerin an interest, volunteer pairtners wis invitit tae parteeicipate in an induction session an askit tae fill in a questionnaire for the ettles o weyin up representation athort Section 75 categories.

Thare wis 41 repones tae this questionnaire wi results as outlined in the table ablo:

Composeetion o Volunteer Pairtners Group
<ul style="list-style-type: none"><li>• <b>Gender:</b> 9 male, 32 female.</li><li>• <b>Age:</b> 20 – 29 (1 member), 30 – 39 (2 members), 40 – 49 (5 members), 50+ (32 members), Prefer no tae say (1 member).</li><li>• <b>Mairital Status:</b> Mairit (25 members), Bidin wi pairtnet (1 member), Single (8 members), Separatit/Divorced (2 members), Weedae'd (4 members), Prefer no tae say (1 member).</li><li>• <b>Dependants:</b> thaim wi (17 members), thaim 'ithoot (23 members), Prefer no tae say (1 member).</li><li>• <b>Disabeelity:</b> thaim wi (7 members), thaim 'ithoot (30 members), Prefer no tae say (3 members).</li><li>• <b>Sexuality:</b> Heterosexual (39 members), Lesbian/Gay (1 member), Bisexual (1 member).</li><li>• <b>Releegion:</b> Protestant (19 members), Catholic (15 members), Ither (3 members), Prefer no tae say (4 members).</li><li>• <b>Racial Group:</b> White (40 members), Black an Minority Ethnic groups (1 member).</li></ul>

## Qualitative Insights frae Engagements

Addeetional qualitative insights reflectin the speceefic needs o a wheen Section 75 groups haes come tae licht athort the early stakehauder engagements. Thir haes helpit tae inform fittin approaches tae the engagement acteevities as weel as contreebutin tae the policy forder an implementation. Some examples o thir insights is notit ablo.

*“A find that langage is chailengin no just here, mair widely ... we talk aboot irrespective o gender etc. instead o sayin inclusive o aw thae identities ... we gey near say we're no fasht aboot thae things ... we shoud be sayin this is an important pairt an acknawledgin that. Thare is a mindset that surroonds this ... fowk say A dinna see colour, A dinna care aboot thae things but we shoud care aboot thaim ... awn it's somebody's leeved experience.”*

*“Makkin an Advance Care Plan lippens on bein able tae write or speak ... whit wey dae we mak it accessible tae fowk wi ither traffeck needs, i.e. thaim wi dementia or a learnin disabeelity ...”*

*“Communications uphaud is awfu important ... deif indiveeduals haes different needs ...”*

*"A like the front-laidit engagements wi the community an voluntar sector; it's the richt type o pairtnery oncome."*

*"Whit stuid oot for me wis the preinciples ... guid tae see the preinciples up front ... for ordinar ye see the unnerpinnin vailies at the end o a document ... Thir is important whan thinkin aboot Advance Care Plannin ... A think thir coud mebbe be stendit a bit mair tae tak in deegnity o fowk in Advance Care Plannin ... some o the mair vailies-grundit langage coud be benefecial for fowk leukin at this policy an professionals engagin wi fowk makkin thair Advance Care Plan."*

## **Actions Taen for tae Uphaud Accessibeelity**

- The completion o Communication Access UK trainin & accreditation by aw Advance Care Plannin Programme Team members.
- Inclusiveness & Accessibeelity Advisement & Uphaud providit by RNIB.
- Addeetional uphaul providit for tae meet needs identifee'd by the deif community.
- The need for aw wittins tae be providit in accessible lay-oots is recogneesed. Forby thon, the need for multilingual an halth literacy uphaul haes been identifee'd.

## **Resairch**

The forder o the policy haes been informed by a commeessioned resairch report frae Ulster University "Whaur ar we nou?"<sup>10</sup> A total o 28.5 per cent o reponents haed heard o the term 'Advance Care Plannin', but anely 7 per cent haed iver taen pairt in a colloque aboot it. Despite this, fower fifts o reponents (82.2 per cent) felt that it wad be comfortin tae knew that thay haed left guidal aboot thair wisses for thair faimly.

The resairch wis grundit on a representative sample o adults frae the NI population aged 18 year an abuin.

## **Ither Data**

Forby the resairch outlined abuin, the follaein soources o quantitative evidence/wittins haes been conseedert:

- Wittins frae the 2011 Census in Northren Ireland, setten furth by the Northren Ireland Stateestics an Resairch Agentrie (NISRA);
- Stateestics for sexual identity in the UK by sex, region an age group, soorced frae the Annual Population Survey setten furth by the Office for Naitional Stateestics;
- Wittins frae the 2019 HSC Staff Survey cairied oot by NISRA;
- The 2020 NI Halth & Social Care warkforce Census setten furth by the Depairtment o Halth, Wittins Analysis Directorate;

<sup>10</sup> Northren Ireland Life an Times Survey (NILT ) is a consteetuent pairt o ARK (Access, Knowledge, Resairch) that's mynt tae uphaul policy forder an debate in Northren Ireland throu providin wittins an creetical analysis. The report can be accessed online: [www.ulster.ac.uk/\\_data/assets/pdf\\_file/0012/819678/Where-ar-we-now-Examining-public-knowledge-and-attitudes-to-palliative-care-and-advance-care-planning-in-NI.pdf](http://www.ulster.ac.uk/_data/assets/pdf_file/0012/819678/Where-ar-we-now-Examining-public-knowledge-and-attitudes-to-palliative-care-and-advance-care-planning-in-NI.pdf)

- The NISRA 2020 Mid-Year Population estimates.

## **Assessment o Impact**

### **Releegious Belief**

#### **Available Evidence – Releegious Belief**

It isna possible tae get a speceefic brakdoun o the releegious belief hauden by service-users, or for aw halth an social care staff. Houiver, we dae knew the brakdoun athort the adult population as per the 2011 Census.<sup>11</sup>

The population o Northren Ireland at the time o the 2011 Census wis 1,810,863, wi releegious belief braken doun as follaes:

- Catholic – 40.8 per cent
- Protestant – 41.6 per cent
- Ither – 0.8 per cent
- Nae Releegion or Releegion no statit – 16.9 per cent

In 2019, NISRA cairied oot the HSC Staff Survey,<sup>12</sup> that collectit some demographic data frae reponents. It is important tae note that, o the 77,781 staff fee'd at the time o the survey, anely 19,094 completit a repone.

O thaim that reponed, community backgrund Releegion wis braken doun as follaes:

- Protestant Community – 42 per cent
- Roman Catholic Community – 45 per cent
- Neither Protestant nor Roman Catholic Community – 13 per cent

Forby thon, releegious belief wis braken doun as follaes:

- Christian – 77 per cent
- Nane – 18 per cent
- Ither Releegion – 5 per cent

### **Assessment o Impact – Releegious Belief**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloquies aboot whit maiters tae thaim, an tae conseedar an record thair wisses, feelins, beliefs an vailiyies, gin thay chuisse tae dae thon. It gies a body a haund tae hae mair chyce

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<sup>11</sup> <https://www.nisra.gov.uk/statistics/census/2011-census>

<sup>12</sup> [HSC Staff Survey 2019 Regional Benchmark Report](#)

an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw an isna expectit tae hae ony differential impact acause o releegious belief.

The data anent releegious belief in Northren Ireland as outlined abuin shaws the predominance o Christian faiths. It is antecipate that this policy coud hae a positive impact on guid relations atween bodies o different releegious beliefs. Advance Care Plannin will allou wisses, feelins, beliefs an vailies tae be discussed, documentit an skared for tae inform futur plannin, comprehendin care, uphaud or treatment.

### **Forderin Equality o Opportunity – Releegious Belief**

For tae gie a heeze tae equality o opportunity, due regard will be gien tae mak shuir o sensiteevity an respect for bodies o aw releegious beliefs whan it comes tae implementin this Advance Care Plannin policy. Proactive measurs will tak in the promotion o the policy tae kirk/belief groups throu relatable messagin as pairt o the public messagin an promotion o the policy.

An Advance Care Plannin Capabeelities Framework haes been pitten thegither for tae uphaud trainin an learr for thaim that gies care, uphaud an treatment. This is mynt tae allou thaim supportin Advance Care Plannin tae prattick in a body-centert wey that uphauds the body's richt tae mak chyces an deceesions, e'en whaur thay differ frae the notions o the body giein care an uphaud.

### **Poleetical opeenion**

#### **Available Evidence – Poleetical opeenion**

Thare is leemitit data available on poleetical opeenion. Houiver, data on the first preference votes per party in NI Assembly Elections 2017<sup>13</sup> shawn ablo can be uised as proxy wittins:

- DUP: 225,413 (28.1 per cent)
- Sinn Féin: 224,245 (27.9 per cent)
- UUP: 103,314 (12.9 per cent)
- SDLP: 95,958 (11.9 per cent)
- Alliance Party: 72,717 (9.1 per cent)
- TUV: 20,523 (2.6 per cent)
- Green: 18,527 (2.3 per cent)
- Independents: 14,407 (1.8 per cent)
- Fowk Afore Tae-come Alliance: 14,100 (1.8 per cent)

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<sup>13</sup> Table 5.1 in [Election Report: Northern Ireland Assembly Election, 2 March 2017 NIAR 20-17](#)

- PUP: 5,590 (0.7 per cent)
- Conservative: 2,399 (0.3 per cent)
- Others: 6,122 (0.8 per cent)

NI Assembly members haes demonstratit cross-party uphaud for the forder o the Advance Care Plannin Policy. This is evidenced in the Committee for Health Inquiry Report on the Impact o COVID-19 in Care Hames (NIA 59/17-22) setten furth on 1 Februar 2021 an in Plenar Session on 27 Aprile 2021 (Hansard Vol. 138, No. 6).

### **Assessment o Impact – Poleetical opeenion**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloquies aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailiyies, gin thay chuisse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw an isna expectit tae hae ony differential impact acause o poleetical opeenion.

### **Forderin Equality o Opportunity – Poleetical opeenion**

For tae gie a heeze tae equality o opportunity, due regard will be gien tae mak shuir o sensiteevity an respect for bodies o aw poleetical beliefs whan it comes tae implementin this Advance Care Plannin policy. Proactive measurs will tak in the promotion o the policy athort aw communities throu relatable messagin as pairt o the public messagin an promotion o the policy.

An Advance Care Plannin Capabeelities Framework will be pitten thegither for tae uphaud trainin an leir for thaim that gies care, uphaud an treatment. This is mynt tae allow thaim that supports fowk in thair Advance Care Plannin tae prattick in a body-centert wey that uphauds the body's richt tae mak chyces an deceesions, e'en whaur thay differ frae the notions o the body giein care an uphaud.

## **Racial Group**

### **Available Evidence – Racial group**

The population o Northren Ireland at the time o the 2011 Census wis 1,810,863, an 1.8 per cent (32,596) o the ordinar resident population belanged minority ethnic groups. The oweraw population brakdoun wis as follaes:

- White – 98.21 per cent (1,778,449)
- Chinese – 0.35 per cent (6,338)
- Erse Traiveler – 0.07 per cent (1,268)
- Indian – 0.34 per cent (6,157)
- Pakistani – 0.06 per cent (1,087)
- Bangladeshi – 0.03 per cent (543)

- Ither Asian – 0.28 per cent (5,070)
- Black Caribbean – 0.02 per cent (362)
- Black African – 0.13 per cent (2354)
- Black Ither – 0.05 per cent (905)
- Mixed – 0.33 per cent (5976)
- Ither – 0.13 per cent (2354)

O the population (aged 3 an abuin) 3.14 per cent conseedert a langage ither nor English as thair main langage. It shoud be notit an aw that o the 98 per cent o fowk for ordinar resident in Northren Ireland on Census Day 2011 that identifee'd thair ethneecity as White, gey near 10 per cent (179,000) wis born ootwi Northren Ireland. This taks in: 19,300 indiveeduals frae Poland, 7,250 frae Lithuania, 4,000 frae Americae, 3,800 frae Germany an 1,650 frae Sooth Africa.

The biggest minority ethnic sub-groups in 2011 wis Chinese (6,300 fowk; up frae 4,100 in 2001), Indian (6,200; up frae 1,600), an Ither Asian (5,000; up frae 200), ilkane accoontin for aroond 0.3 per cent o the ordinar resident population (Table DC2248NI). Comprehendin the 1,300 Erse Traivelers, 1.8 per cent (32,400) o ordinar residents belanged Minority Ethnic groups in 2011, mair nor dooble the proportion in 2001 (0.8 per cent).

It can be expectit that the nummer o fowk born ootwi Northren Ireland haes eikit signeeficantly sin the 2011 Census.

The 2011 Census results shaws a differ in the age profile o the Erse Traiveler community by the white population. While 78 per cent o Traivelers is aged unner 45, (compared wi 61 per cent o thaim o White ethneecity), anely 6.4 per cent (83 bodies) is aged 65 or abuin, compared wi 15 per cent o thaim o White ethneecity.

The smaw nummer an proportion o aulder Traivelers is a reflection o thair lawer life expectancy. The Aw-Ireland Traiveler Halth Study (2010)<sup>14</sup> fand that male Traivelers in Ireland (comprehendin Northren Ireland) haed a life expectancy at birth o 61.7 year, equeevalent tae thon o the general population in the 1940s. For female Traivelers, life expectancy wis 70.1 years, seemilar tae thon o the general population in the 1960s.<sup>15</sup>

## **Assessment o Impact – Racial Group**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloques aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailyies, gin thay chuisse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw an isna expectit tae hae ony differential impact acause o racial group.

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<sup>14</sup> DHSSPS (2010) Aw-Ireland Traiveler Halth Study. University College Dublin. Available at: <http://www.dhsspsni.gov.uk/aihs.pdf>

<sup>15</sup> It is wirth notin an aw that tho Census 2011 enumeratit a total o 1,301 Traivelers in Northren Ireland, the Aw-Ireland Traiveler Halth Study (UCD / DHSSPS, 2010) fand a total o 1,562 Traiveler familiies leevin in Northren Ireland, wi an estimatit Traiveler population o 3,905.

Advance Care Plannin coud gie an inlat for bodies o different racial groups tae hae collegues wi thaim that gies care, uphaud or treatment that coud tak in skarin wittins aboot thair ethnic an cultural beliefs an tradeetions. This might coud gie a heeze tae mair unnerstaundin atween bodies o different racial groups as weel as helpin tae mak shuir that different ethnic/cultural beliefs an tradeetions, whan important tae a body, is reflectit accordindly in the care, uphaud or treatment that the body gets.

It coud be expectit an aw that the policy will hae a positive impact on racial groups wi lawer life expectancy, as it will creaut inlats for the expression o chyce in care, uphaud or treatment that mebbe haesna been available afore the introduction o the Advance Care Plannin policy.

### **Forderin Equality o Opportunity – Racial Group**

For tae gie a heeze tae equality o opportunity, due regaird will be gien tae mak shuir o sensiteevity an respect for bodies o aw racial groups whan it comes tae implementin this Advance Care Plannin policy. The need for multilingual uphaud haes been identifee'd. Thare is indications that some ethnic groups is no sae likely tae access services. This is a factor that will be conseedert whan implementin the policy for tae mak shuir that ony exeestin barriers is meetigatit for tae uphaud equitable access. Proactive meisurs will tak in the promotion o the policy tae aw racial groups throu relatable messagin as pairt o the public messagin an promotion o the policy.

An Advance Care Plannin Capabeelities Framework will be pitten thegither for tae uphaud trainin an lear for thaim that gies care, uphaud an treatment. This is mynt tae allow thaim that supports fowk in thair Advance Care Plannin tae prattick in a body-centert wey that uphauds the body's richt tae mak chyces an deceesions, e'en whaur thay differ frae the notions o the body giein care an uphaud.

## **Age**

### **Available Evidence – Age**

Northren Ireland's average age gaed up frae 34 year tae 37 year atween the 2001 an 2011 Censuses. Ower the same period, the skare o the population representit by bairns aged unner 16 years fell frae 24 per cent tae 21 per cent, while the proportion o fowk aged 65 year an abuin rase frae 13 per cent tae 15 per cent.

Compared wi the 2001 Census, the nummer o fowk aged 65 year an abuin leevin in NI gaed up by 18 per cent (40,400) tae 263,700 on Census Day 2011.

Atween 2002 an 2012, the nummer o fowk aged 60-84 rase by 20 per cent, while thaim aged 85+ rase by 38 per cent. This shaws an agein population demographic.

The 2020 Mid-year Population estimates<sup>16</sup> shaws that the present population o Northren Ireland is 1,895,510 wi 441,108 (23 per cent) o thaim aged unner 18 an 1,454,402 (77 per cent) aged ower 18.

Resairch cairied oot by iReach on behauf o the Aw-Ireland Institute o Hospice an Pailiative Care (AIIHPC)<sup>17</sup> indicatit that 73 per cent o NI reponents grees (grees or strangly grees) that thay wad like tae be supportit tae discuss an write doun thair wisses an preferences for care at the end o life. Thare wis nae knawable variation athort the age bands surveyed, wi results as follaes:

- 73 per cent o thaim aged 18-34 expressed this preference,
- 71 per cent o thaim aged 35-55 expressed this preference, an
- 78 per cent o thaim aged 55+ expressed this preference.

In Februar 2007, the Alzheimer's Society set furth a fouthy study on the social an economic impact o dementia in the UK. The resairch,<sup>18</sup> commeessioned throu King's College London an the London Schuil o Economics, provides a detailed an strenthie pictur o the prevalence an economic impact o dementia in the UK. This report estimates that ane in 14 fowk abuin 65 year o age an ane in sax fowk abuin 80 year o age haes a furm o dementia. Anither report setten furth by Alzheimer's Society: 'Dementia 2013: The hidden vyce o laneliness'<sup>19</sup> indicatit that 18,862 fowk in NI haed dementia.

### **Assessment o Impact – Age**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloquies aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailyies, gin thay chuisse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw for aw adults aged 18 year an abuin.

Traditionally, Advance Care Plannin haes been associate wi end-o-life an pailiative care or thocht tae be relevant anely tae adulder fowk. This policy is mynt tae provide a framework for Advance Care Plannin that stends tae aw adults aged 18 year an abuin. This oncome is mynt tae upsteer adults o aw ages an stages o life tae think aboot an plan for thair futur needs.

In Northren Ireland, bodies ablo the age o 18 is in the minority, at the meenit estimatit tae be less nor a quarter o the population (23 per cent).

This policy disna tak in bairns an young fowk ablo the age o 18 direct. The rationale for the policy scowth for thaim aged 18 year an abuin bigs on ethical preinciples o proportionality an conseederation o legal aspects whaur proveesion is different for thaim ablo the age o 18 by thaim abuin the age o 18.

<sup>16</sup> <https://www.nisra.gov.uk/publications/2020-mid-year-population-estimates-northern-ireland>.

<sup>17</sup> <https://aiihpc.org/wp-content/uploads/2020/10/Palliative-Care-Study-NI-July-2020-V1.2.pdf>

<sup>18</sup> LSE, King's College London, Alzheimer's Society. Dementia UK: The Full Report, 2007 [alzheimers.org.uk](http://alzheimers.org.uk)

<sup>19</sup> [Dementia 2013: The hidden voice of loneliness \(alzheimers.org.uk\)](http://alzheimers.org.uk)

This deceesion haes been informed by legal an prattickal conseederations as outlined ablo:

It is recogneeseed that the needs o bairns an young fowk in the unner-18 age group is signeeficantly different an wad need a speceefically teylored oncome. The Bairns (NI) Order 1995<sup>20</sup> recogneesees that bairns shoud be gien a vyce in whit happens tae thaim, an inlays for wirkin in pairtnery wi bairns shoud be gien, as far as thair age an development allous. The Bairns (NI) Order 1995 needs the bairn's<sup>21</sup> weel tae be gien paramoont conseederation.

Mairatour, exeestin legislation an prattick frameworks that unnerpins this policy disna align wi proveesion for unner-18s. The Age o Majority (NI) Act 1969<sup>22</sup> needs a body tae hae won tae the age o 18 afore thay can mak a wheen contractual deceesions. Likewise, the law generally disna allou onyboddy ablo the age o 18 tae mak a statutor will.

The policy taks in Advance Deceesions tae refuse Treatment (ADRT). Whaur this is a body's chyce, tae be valid, the body maun be 18 or abuin an hae the capacity tae mak the deceesion.

The inclusion o thaim aged 16 tae 17 for parts o the Mental Capacity Act (2016) legislation is acknawledged, houiver, the policy scowth bein for thaim aged 18 year an abuin, grundit on on ethical preinciples o proportionality.

Thare is a potential indirect positive impact for thaim aged unner 18 in that the policy taks in a proveesion for conseederin dependants in Advance Care Plannin. It is antecipate that it will offer potential benefits for bairns an young fowk as weel as vulnerable adults, gin a paurent or carer wi Advance Care Plannin in place comes tae be seek or tine capacity.

Aw Section 75 categories o the adult population (aged ower 18) is expectit tae benefit frae this policy. A core mynt o the policy is tae stend the prattick o Advance Care Plannin ayont pailiative an end-o-life care, tae normaleese Advance Care Plannin collegues an, ideally, tae help mak shuir that sic collegues happens afore ony crisis the like o the diagnosis o a serious seekness.

### **Meetigations/Alternative Policies – Age**

As outlined abuin, the rationale for the policy scowth for thaim aged 18 year an abuin is grundit on ethical preinciples o proportionality an conseederation o legal aspects whaur proveesion is different for thaim ablo the age o 18 by thaim aged 18 an abuin. Alternative proveesions for bairns an young fowk wi pailiative care needs is outlined in the straategy "Providin Hie-quality Pailiative Care for Oor Bairns"<sup>23</sup>

that states:

*"Care an uphaud will be planned, takkin account o the wisses an needs o the bairn an thair faimily, an will focus on the best interests o the bairn an thair quality o life."*

<sup>20</sup> [The Children \(Northern Ireland\) Order 1995 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

<sup>21</sup> A body ablo the age o 18 is defined as a "bairn" unner the Bairns (NI) Order 1995 an unner internaitional law.

<sup>22</sup> [Age o Majority Act \(Northren Ireland\) 1969 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

<sup>23</sup> Department o Halth, Providin Hie-quality Pailiative Care for Oor Bairns: A Straegy for Bairns' Pailiative an End-o-life Care 2016 – 26.

## **Forderin Equality o Opportunity – Age**

For tae gie a heeze tae equality o opportunity, due regaird will be gien tae mak shuir o sensitivitiey an respect for bodies o aw age groups whan it comes tae implementin this Advance Care Plannin policy. Proactive measurs will tak in the promotion o the policy tae different age groups throu relatable messagin as pairt o the public messagin an promotion o the policy.

## **Mairital Status**

### **Available Evidence – Mairital Status**

The 2011 Census data provides wittins on mairital status. It shawed that gey near hauf (48 per cent) o fowk aged 16 years an abuin wis mairit, an mair nor a third (36 per cent) wis single. Just ower 1,200 fowk (0.1 per cent) wis in registert same-sex ceevil pairtneries in Mairch 2011. Anither 9.4 per cent o ordinar residents wis aither separatit, divorced or formerly in a same-sex ceevil pairtnery, while the remeenin 6.8 per cent wis aither weedae'd or a survivin partner.

### **Assessment o Impact – Mairital Status**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloquies aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailifies, gin thay chuse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw an isna expectit tae hae ony differential impact acause o mairital status.

## **Forderin Equality o Opportunity – Mairital Status**

For tae gie a heeze tae equality o opportunity, due regaird will be gien tae mak shuir o sensitivitiey an respect for bodies o different mairital status whan it comes tae implementin this Advance Care Plannin policy. Proactive measurs will tak in the promotion o the policy tae bodies o different mairital status throu relatable messagin as pairt o the public messagin/promotion o the policy.

Gin evidence o ony potential impacts craps up, this will be explored for tae identifee fittin meetigations.

## **Sexual Orientation**

### **Available Evidence – Sexual Orientation**

It is acknawledged that accurate feegurs isna available for the sexual orientation o the general population, an mony estimates varies. NISRA, alang wi ither UK Census offices, haes proponees in place tae address this in the 2021 Census.

The 2012 Life an Times Survey<sup>24</sup> interviewed 1204 adults tae estaiblisch thair sexual orientation.

- 98 per cent o reponents identifee'd thairsels as Heterosexual/Straucht,
- 1 per cent as Gay/Lesbian, an
- 1 per cent providit Nae evidence/Refusal.

Feegars setten furth by the Office o Naitional Stateestics in 2010 recordit that 0.9 per cent o the UK population identifee'd thairsels as gay or lesbian, while another 0.5 per cent identifee'd thairsels as bisexual (Meisurin Sexual Identity: An Assessment Report<sup>25</sup>). It is likely that the true feegurs is signeeficantly heicher.

Phase I an II stakehauder engagement haes includit feedback frae groups representin bodies that identifees as LGBTQ+. Speceefic pynts anent the experiences o LGBTQ+ bodies haes helpit tae inform reveesions o the draucht policy. Thir taks in: recogneetion that the tradeetional faimily structur disna aye applee; fashes that LGBTQ+ relationships isna aye acknawledged in care settins an suggestions that langage shoud reflect incluseevity.

*"leukit at it wi an LGBT lens ... an whan it comes tae barriers for LGBT fowk ... Quaistens aboot faimily members an deceesion-makkin an thair visibeelity, thair capacity tae come oot 'ithin care environments an the sauftie an barriers aroond that"*

*"for me thinkin aboot the LGBT+ body, after the barrier is that fowk disna speir aboot sexual orientation or gender identity ... fowk isna speirt ... the responsibeelity is on the client tae oot thairsels tae be fully recogneesed as wha they ar, as thair hale sels."*

## **Assessment o Impact – Sexual Orientation**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloques aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailyies, gin thay chuisse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw, an we jalouse that this policy coud hae a positive impact on bodies o different sexual orientation.

Advance Care Plannin will allou wisses, feelins, beliefs an vailyies tae be discussed, documentit an skared for tae inform futur plannin, care, uphaud or treatment. This coud, gin the body wisses, tak in maiters anent thair sexual orientation an relationships.

Tharefore, Advance Care Plannin coud gie an inlat for bodies o different sexual orientations tae hae colloques wi thaim that gies care, uphaud or treatment. This coud tak in skarin wittins aboot thair sexual orientation. This nicht coud gie a heeze tae mair unnerstaundin between bodies o different sexual orientations as weel as helpin tae mak shuir that whit maiters tae the body is reflectit accordindly in the care, uphaud or treatment that thay get.

<sup>24</sup> Northern Ireland Life an Times Survey 2012 ([ark.ac.uk](http://ark.ac.uk))

<sup>25</sup> <https://data.gov.uk/dataset/e6033627-3106-47a9-a3fb-4bcaa34c1bcb/measuring-sexual-identity-assessment-report>

It could be expectit an aw that the policy will hae a positive impact on bodies that identifees as LGBTQ+ that could hae non-traditional family structures, as it will creat mair inlat for the expression o chyce in thair care, uphaul or treatment. The policy purposely uses the phrase "thaim that's important tae the body" tae be inclusive an reflect non-traditional family structures.

### **Forderin Equality o Opportunity – Sexual Orientation**

For tae gie a heeze tae equality o opportunity, due regard will be gien tae mak shuir o sensitivitiy an respect for bodies o aw sexual orientations whan it comes tae implementin this Advance Care Plannin policy. Proactive measurs will tak in the promotion o the policy tae bodies o different sexual orientation throu relatable messagin as pairt o the public messagin an promotion o the policy.

An Advance Care Plannin Capabilities Framework will be pitten thegither for tae uphaul trainin an leir. This is mynt tae allow thaim that supports fowk in thair Advance Care Plannin tae prattick in a body-centert wey that uphauds the body's richt tae mak chyces an deceesions, e'en whaur thay differ frae the notions o the body giein care an uphaul.

## **Gender**

### **Available Evidence – Gender**

The 2011 Census data showed that 49 per cent o aw ordinary residents in Northern Ireland is male, wi 51 per cent o the population female. Forby thon, a smaw nummer identifees as neither male nor female or as baith.

### **Assessment o Impact – Gender**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an practical colloquies aboot whit maiters tae thaim, an tae consider an record thair wisses, feelins, beliefs an vailifies, gin thay chuse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw an isna expectit tae hae ony differential impact because o gender.

It is anticipate that this policy could hae a positive impact on bodies o different gender identities. Advance Care Plannin will allow wisses, feelins, beliefs an vailifies tae be discussed, documentit an skared for tae inform futur plannin, care, uphaul or treatment. This can, gin the body wisses, tak in maiters anent thair gender identity.

Advance Care Plannin could gie an inlat for bodies o different gender identities tae hae colloquies wi thaim that gies care, uphaul or treatment. This might could gie a heeze tae mair unnerstaundin between bodies o different gender identity.

## **Forderin Equality o Opportunity – Gender**

For tae gie a heeze tae equality o opportunity, due regaird will be gien tae mak shuir o sensitivitiey an respect for bodies o aw gender identities whan it comes tae implementin this Advance Care Plannin policy. Proactive measurs will tak in the promotion o the policy tae bodies o different genders throu relatable messagin as pairt o the public messagin an promotion o the policy.

An Advance Care Plannin Capabeelities Framework will be pitten thegither for tae uphaud trainin an leir. This is mynt tae allou thaim that supports fowk in thair Advance Care Plannin tae prattick in a body-centert wey that uphauds the body's richt tae mak chyces an deceesions, e'en whaur thay differ frae the notions o the body giein care an uphaud.

## **Disabeelity**

### **Available Evidence – Disabeelity**

In 2011, Census data shawed that just ower ane in five o the ordinar resident population (21 per cent) haed a lang-term halth problem or disabeelity that leemitit thair day-tae-day acteevities. The maist common lang-term condeetions amang the ordinar resident population wis:

- a mobeelity or dexterity problem (11 per cent);
- lang-term pain or discomfort (10 per cent);
- cuttiness o breith or difficulty breithin (8.7 per cent);
- chronic seekness (6.5 per cent); an
- an emotional, psychological or mental halth condeetion (5.8 per cent).

Early stakehauder engagement includit consultation wi the Heid Equality Commeessioner an staff frae the Equality Commeesion for Northren Ireland. The importance o the Unitit Nations Convention on the Richts o Bodies wi Disabeelities, UNCRPD, wis notit, wi speceefic reference made tae Airticle 12 (Equal recogneetion afore the law) an Airticle 25 (Halth), as weel as General Comment No. 1 o the UN Committee on the Richts o Bodies wi Disabeelities that elaborates on the obligations o Airticle 12.<sup>26</sup>

It is recogneeseed that fowk wi a disabeelity isna a homogeneous group. Speceefic pynts anent the differin needs o bodies wi different disabeelities wis notit durin stakehauder engagements.

Ae example is whit wey different traiffeck uphaud is needit for thaim in the deif community

*“Aften the first assumption is that the body will be a sign langage uiser an need an interpreter; houiver, this isna the case for the majority o deif fowk that lip-reads. It is important tae recogneese baith traiffeck preferences.”*

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<sup>26</sup> <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

*"Whit is maist important is that wittins needs tae be in BSL an ISL format ... tae mak it accessible on a wabsteid in baith formats ... Advocacy uphaud will be important an aw ... uise scenarios ... tae expleen"*

Forby thon, durin the stakehauder engagements, differs in the levels o awaurness o the concept o Advance Care Plannin atween different disabeelity groups haes come tae licht;

*thaim wi a learnin disabeelity an thaim that's important tae the body wi a learnin disabeelity haed experience o plannin futur care "body-centert plannin isna new tae the Learnin Disabeelity warld ... This is whit we dae ilkaday"*

This wis in contrast tae some members o the deif community that commentit that;

*"meaninfu body-centert plannin for aw. – is a new concept for the deif community"*

### **Assessment o Impact – Disabeelity**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloques aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailyies, gin thay chuse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw, an we jalouse that the Advance Care Plannin policy coud hae a positive impact on bodies wi a disabeelity.

Advance Care Plannin will allou wisses, feelins, beliefs an vailyies tae be discussed, documentit an skared for tae inform futur plannin, care, uphaud or treatment. This coud, gin the body wisses, tak in maiters anent thair disabeelity. Tharefore, Advance Care Plannin coud gie an inlat for bodies wi a disabeelity tae skare wittins wi thaim that gies care, uphaud or treatment.

This might coud gie a heeze tae mair unnerstaundin o the needs o bodies wi a disabeelity as weel as helpin tae mak shuir that thay hae mair inlat for chyce an control in thair care, uphaud or treatment. It coud be expectit that the policy will help mak shuir that the body's beliefs an vailyies is respectit an that this is reflectit accordindly in the care, uphaud or treatment that thay get.

Forby thon, it coud be expectit that the policy will hae a positive impact on bodies wi a disabeelity wi lawer life expectancy, as it will creaut mair inlat for the expression o chyce in care an treatment.

### **Forderin Equality o Opportunity – Disabeelity**

For tae gie a heeze tae equality o opportunity, due regaird will be gien tae mak shuir o sensitivitiy an respect for the speceefic needs o bodies wi a disabeelity whan it comes tae implementin this Advance Care Plannin policy (e.g. communications needs, reasonable adjustments). Whaur the speceefic needs o bodies wi different disabeelities arises, thir will be

explored for tae identifee fittin meetigations, as wis the case durin the stakehauder engagements.

Proactive meisurs will tak in the promotion o the policy tae bodies wi disabeelities throu relatable messagin as pairt o the public messagin/promotion o the policy.

Thare will be ongaun wark wi fowk wi disabeelities tae mak shuir that the policy is presentit in accessible lay-oots an meets the multipleecity o needs in implementation.

An Advance Care Plannin Capabeelities Framework will be pitten thegither for tae uphaud trainin an leir. This is mynt tae allou thaim that supports fowk in thair Advance Care Plannin tae prattick in a body-centert wey that uphauds the body's richt tae mak chyces an deceesions, e'en whaur thay differ frae the notions o the body giein care an uphaud.

## Dependants

### Available Evidence – Dependants

In 2011, ae-third (34 per cent) o hoosehauds in Northren Ireland conteened dependent bairns, doun frae 36 per cent in 2001. Twa-fifts (40 per cent) o hoosehauds conteened at least ae body wi a lang-term halth problem or disabeelity; made up o thae hoosehauds wi dependent bairns (9.2 per cent) an thaim wi nae dependent bairns (31 per cent).

In Mairch 2011, 5.8 per cent o hoosehauds conteened dependent bairns an nae adults in employ.

In the 2011 Census, 214,000 fowk in Northren Ireland wis providin some furm o unpeyed care, equatin tae aboot ane in echt residents in Northren Ireland (12 per cent). This compares wi 185,066 in 2001, growthe o 16 per cent.

Feegurs shaws that: mair nor hauf o unpeyed carers (122,000, 57 per cent) wis giein care for atween 1 an 19 oors a week, while 35,000 (17 per cent) wis engaged for 20 tae 49 oors a week. Just ower a quarter (56,000, 26 per cent) haed carin responsibilities for 50 or mair oors a week.

Uisin the 2017 mid-year population estimates, that shaws a 3 per cent eik in population sin 2011; thare is like tae be aboot 220,000 fowk in Northren Ireland wi some furm o carin role.<sup>27</sup>

A recent report setten furth by Carers UK on October 2020<sup>28</sup> citit that thare wis 212,000 unpeyed careers in Northren Ireland an haes estimatit that the COVID-19 pandemic haes resultit in an addeetional 98,000 fowk new tae carin in Northren Ireland. Wirkin frae

<sup>27</sup> [Carers in Northern Ireland: Some principal statistics – Research Matters \(assemblyresearchmatters.org\)](#)

<sup>28</sup> [Carin ahint closed doors: sax months on, The conteened impact o the coronavirus \(COVID-19\) pandemic on unpeyed carers, Carers UK October 2020 Caring behind closed doors\\_Oct20.pdf \(carersuk.org\)](#)

population projections, Carers UK suggests that there is as many as 310,000 unpaid carers in Northern Ireland at the moment.<sup>29</sup>

The inclusion of provisions for dependants in Advance Care Planning was brought up in a number of Stakeholder Engagements. This was a particular concern for the parents of vulnerable adults that cited that the care of their children was their main reason for engaging in Advance Care Planning.

*"There are two different pieces of work ... For anyone or us our own Advance Care Planning colleague ... and then, what about this other adult that has responsibility for, that I love and that I'm wanting the right things for?"*

This issue was acknowledged, and the revised policy draft outlines a components model for Advance Care Planning that takes in an element 'within the 'Personal' component for considering dependants in a body's Advance Care Planning.

### **Assessment o Impact – Dependants**

Advance Care Planning makes sure that people have the input they need to be realistic and practical colleagues about what matters to them, and to consider and record their wishes, feelings, beliefs and values, given the choice to do so. It gives a body a hand to have more choice and control over decisions, comprehending plans for their future care and treatment. Advance Care Planning is like having a positive impact overall.

The policy might could have a positive impact on them with dependants, as it will allow Advance Care Planning colleagues to take into account the body's wishes, feelings, beliefs and values about their dependants. It is not anticipated that this will be a hinderance to them in terms of dependants.

### **Ensuring Equality o Opportunity – Dependants**

For there to be a sense of equality and opportunity, due regard will be given to making sure of sensitivity and respect for the specific needs of bodies with caring responsibilities when it comes to implementing the Advance Care Planning policy (e.g. reasonable adjustments). Proactive measures will take into account the promotion of the policy to bodies with caring responsibilities through relatable messaging as part of the public messaging and promotion of the policy. Training and learning measures for staff brought in as an outcome of policy implementation will focus on the needs of them with caring responsibilities.

### **Multiple Identities**

#### **Available Evidence – Multiple Identities**

It's not easy working out the full extent of impacts on bodies with caring responsibilities before planning the implementation of the policy with detailed actions.

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<sup>29</sup> Carers' Week (2020) Carers' Week Research Report CW\_2020\_Research\_Report\_WAB.pdf ([carersuk.org](http://carersuk.org))

## **Assessment o Impact – Multiple Identities**

Advance Care Plannin maks shuir that fowk haes the inlat tae hae realistic an prattickal colloquies aboot whit maiters tae thaim, an tae conseeder an record thair wisses, feelins, beliefs an vailyies, gin thay chuisse tae dae thon. It gies a body a haund tae hae mair chyce an control ower deceesions, comprehendin plans for thair futur care an treatment. Advance Care Plannin is like tae hae a positive impact oweraw an isna expectit tae hae ony differential impact on the grunds o sindry identities. Acause o the body-centert natur o the oncome tae Advance Care Plannin that the policy will uphaud, we jalouse that thare will be signeeficant positive impacts on bodies in this category.

## **Forderin Equality o Opportunity – Multiple Identities**

For tae gie a heeze tae equality o opportunity, due regaird will be gien tae mak shuir o sensitivitiy an respect for the speceefic needs o bodies wi sindry identities whan it comes tae implementin this Advance Care Plannin policy. Gin evidence o ony potential impacts comes tae the fore, this will be explored for tae identifee fittin meetigations.

## Human Rights

AIRICLE (ECHR/ HRA 1998)	POSITIVE IMPACT	NEGATIVE IMPACT = human richt interfered wi or restrictit	NEUTRAL IMPACT
Airticle 2 – Richt tae life	<input checked="" type="checkbox"/>		
Airticle 3 – Richt tae freedom frae tortur, inhuman or degradin treatment or punishment	<input checked="" type="checkbox"/>		
Airticle 4 – Richt tae freedom frae slavery, servitude & forced or compulsitor wark			<input checked="" type="checkbox"/>
Airticle 5 – Richt tae leeberthy & security o ain sel			<input checked="" type="checkbox"/>
Airticle 6 – Richt tae a fair & public trial 'ithin a reasonable time			<input checked="" type="checkbox"/>
Airticle 7 – Richt tae freedom frae retrospective creeminal law & nae punishment 'ithoot law.			<input checked="" type="checkbox"/>
Airticle 8 – Richt tae respect for private & faimily life, hame an correspondence.	<input checked="" type="checkbox"/>		
Airticle 9 – Richt tae freedom o thocht, conscience & Releegion	<input checked="" type="checkbox"/>		
Airticle 10 – Richt tae freedom o expression	<input checked="" type="checkbox"/>		
Airticle 11 – Richt tae freedom o assembly & association			<input checked="" type="checkbox"/>
Airticle 12 – Richt tae mairy & stert a faimily			<input checked="" type="checkbox"/>
Airticle 14 – Prohibeetion o dissecremination in the enjeyment o the convention richts	<input checked="" type="checkbox"/>		
1st protocol Airticle 1 – Richt tae a peacefu enjeyment o possessions & pertection o haudin	<input checked="" type="checkbox"/>		
1st protocol Airticle 2 – Richt o access tae lear			<input checked="" type="checkbox"/>
ARTICLE – UNCRPD	POSITIVE IMPACT	NEGATIVE IMPACT = human richt interfered wi or restrictit	NEUTRAL IMPACT
Airticle 12 (Equal recogneetion afore the law)	<input checked="" type="checkbox"/>		
Airticle 25 (Halth) o the Unitit Nations Convention on the Richts o Bodies wi Disabeelities	<input checked="" type="checkbox"/>		

## **Guid Relations**

‘Guid Relations’ is defined by the Equality Commeesion as: “The growthe o relationships an structurs for Northren Ireland that awns the releegious, poleetrical an racial context o this society, an that seeks tae gie a heeze tae respect, equity an trust, an embrace diversity in aw its forms.”<sup>30</sup>

The Advance Care Plannin policy coud hae an indirect positive impact on guid relations atween bodies wi differin releegious beliefs, bodies wi differin poleetrical opeenions or atween bodies frae different racial groups. Advance Care Plannin will allow wisses, feelins, beliefs an vailiyies tae be discussed, documentit an skared. This coud gie an inlat for bodies o different opeenions, beliefs an cultural backgrunds tae hae collegues. This might coud gie a heeze tae mair unnerstaundin.

The policy is supportit by a Capabeelities Framework for thaim giein care, uphaud or treatment. Trainin will allow thaim that supports a body’s Advance Care Plannin tae prattick in a body-centert wey that uphauds the body’s richt tae mak chyces an deceesions, e'en whaur they differ frae the notions o the body giein care an uphaud.

## **Conclusion**

This EQIA haes uised available evidence tae conseeder aw nine Equality groups. It is evident that, oweraw, the Advance Care Plannin policy is expectit tae hae a positive impact for aw adults aged 18 an abuin. Alternative proveesions for bairns an young fowk wi pailiative care needs is outlined in the straitegy “Providin Hie-quality Pailiative Care for Oor Bairns”<sup>31</sup>

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<sup>30</sup> [www.equalityni.org/ECNI/media/ECNI/Publications/Employers%20and%20Service%20Providers/Public%20Authorities/Public-Authorities-Summary\\_Guide.pdf](http://www.equalityni.org/ECNI/media/ECNI/Publications/Employers%20and%20Service%20Providers/Public%20Authorities/Public-Authorities-Summary_Guide.pdf)

<sup>31</sup> Department o Halth, Providin Hie-quality Pailiative Care for Oor Bairns: A Straitegy for Bairns' Pailiative an End-o-life Care 2016 – 26.

## **Monitorin an review arreengements**

### **Proponit monitorin**

A new affcomes framework will be pitten thegither for tae meisur affcomes o the policy. Ony potential impacts o the policy, projects or service developments unnerstaen tae meet the implementation o the policy will be dealt wi, as fittin, at the indiveedual policy, project or service development level.

### **Co-design/Co-production**

The puil o volunteer pairtners recruitit in pairtnery wi the Patient an Client Cooncil will be drawn upo for tae uphaud co-production/co-design acteevities at sindry stages o the Advance Care Plannin Programme o wark. As the policy forder an implementation progresses, thir volunteer pairtners will be offert the inlat tae contreebute in the follaein auries:

- Shapin whit wey Advance Care Plannin will be pitten intae prattick tae mak shuir that awbody haes the inlat tae hae Advance Care Plannin collegues.
- Shapin the trainin an lear for indiveeduals an professional groups that gies care an uphaud.
- Helpin tae creaut messages for the public – tae mak shuir that awbody knows whit Advance Care Plannin is an unnerstaunds whit for it is an important thing that aw adults, at ony stage o life, shoud conseeder.
- Reviewin the Advance Care Plannin Programme o wark an the differ it haes made tae fowk by forderin an greein weys o meisurin the affcomes an impact o the policy an its implementation.

The ineetial focus will be tae creaut public messages aboot the Advance Care Plannin policy tae uphaud the lench o the public consultation.

### **Advance Care Plannin Capabeelities Framework**

An Advance Care Plannin Capabeelities Framework will be pitten thegither in pairtnery wi Educators tae uphaud trainin an lear for thaim that gies care, uphaud or treatment. The gree'd Capabeelities Framework will unnerpin the programme o trainin an lear tae be pitten thegither for tae uphaud the implementation o the Advance Care Plannin policy.