

PART II

**PUBLIC CONSULTATION ON THE FUTURE DEVELOPMENT OF
CLINICAL GENETIC SERVICES**

EQUALITY IMPACT ASSESSMENT

**Department of Health, Social Services and Public Safety
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1. INTRODUCTION

- 1.1 The Department has developed this equality impact assessment (EQIA) to address proposals for the future development of clinical genetic services.
- 1.2 Section 75 of the Northern Ireland Act 1998 requires all public authorities, in carrying out their functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity -
- between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
 - between men and women generally;
 - between persons with a disability and persons without; and
 - between persons with dependants and persons without.
- 1.3 In addition, without prejudice to the above obligation, public authorities must also, in carrying out their functions relating to Northern Ireland, have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group.
- 1.4 Schedule 9 of the Act requires public authorities to prepare Equality Schemes, which should state, amongst other things, the authority's arrangements for assessing the likely impact of policies adopted, or proposed to be adopted, by the authority on the promotion of equality of opportunity. Schedule 9 also requires a public authority, in publishing the results of an assessment, to give details of any consideration given to measures, which might mitigate any adverse impact of the policy on the promotion of equality of opportunity, and alternative policies, which might better achieve the promotion of equality of opportunity.

- 1.5 Equality Schemes are in place for the Department of Health, Social Services and Public Safety and all Health and Social Services Boards and Trusts.

- 1.6 The proposals in the Review of Clinical Genetic Services aim to improve the quality and accessibility of services for patients across Northern Ireland. Proposals for conducting equality impact assessments on a region-wide basis were submitted by the Department and its associated bodies to the Equality Commission for Northern Ireland in June 2001. This Equality Impact Assessment has been conducted and agreed in accordance with those proposals.

2 FOCUS OF EQUALITY IMPACT ASSESSMENT

2.0 The Department of Health, Social Services and Public Safety and its associated bodies are committed to promoting equality of opportunity and implementing the Government's New Targeting Social Need (TSN) policy. Specific areas of concern within the Department's business area include:

- the inequalities which exist in health, many of which are associated with differences between affluent and deprived communities;
- the difficulties in accessing services faced by people in rural areas; and
- that people in some of the Section 75 equality groups may not, for various reasons, use health and social services to the same extent as people from other population groups with similar levels of morbidity.

2.1 Against this background, the overall aims are:

- to promote equality of opportunity of access to health and social services for people in equal need;
- to ensure equity in the allocation of resources, reflecting as far as possible variations in need across the country; and
- through New TSN, to tackle inequalities in health and social well-being, and in need for and access to, health and social care.

- 2.2 In assessing the impact of the Clinical Genetics Review on Section 75 equality groups, the equality impact assessment considers the extent to which the proposals support or contribute to these aims.
- 2.3 This equality impact assessment draws on the information contained in the main body of the Clinical Genetic Services Report and it should be read in conjunction with this Report.
- 2.4 In July 2002 the then Minister, Bairbre de Brún, agreed that the Department should undertake a review of Clinical Genetic Services to assess the need for genetics services, in light of national and international developments in genetics and the implications for health. The Review of Clinical Genetics aims to address specifically the regional clinical genetics service and, in particular, how it needs to develop to meet the anticipated needs of the population over the next 5-10 years.
- 2.5 In the course of its work, the Review adopted a participative approach by holding a multidisciplinary workshop and meetings with professionals and representatives from the voluntary sector. A patient satisfaction survey also helped to provide valuable information on the experience of patients and their families attending the clinical genetic clinics.
- 2.6 In reaching its conclusions, the Clinical Genetic Services Review has considered the potential impact which the proposals may have on the nine equality groups. On the whole, the implementation of the Review will have a positive impact on clinical genetic services. For example, proposals for the appointment of additional staffing, provision of additional workspace, and the procurement and replacement of equipment will help to improve the quality and speed of access to care for genetics patients.
- 2.7 This equality impact assessment addresses patient access to clinical genetic services across Northern Ireland in line with the Department's aim to promote equality of opportunity of access to health and personal social services.

3 CONSIDERATION OF AVAILABLE DATA

3.0 Statistical data on the nine equality groups was provided by the Department's Information and Analysis Unit. A breakdown of the data sources is outlined below.

3.1 Northern Ireland Census

3.2 A census of population is normally taken every ten years and is carried out by the Census Office for Northern Ireland (CONI). The census provides essential statistical information about the population and households for all parts of the country. The most recent results suitable for use in this analysis are from the 1991 census returns. However, data from the 2001 census was available in relation to people from different ethnic communities and was used for this equality impact assessment.

3.3 Hospital Inpatients System

3.4 The Hospital Inpatients System (HIS) processes information relating to inpatient stays in hospital. The source information HIS is the Patient Administration System (PAS) maintained in all acute hospital sites in Northern Ireland.

3.5 First Preference Votes

3.6 Votes cast in an election based on proportional representation which indicated the voter's first or only preference.

3.7 Ethnic Minority Communities in Northern Ireland

3.8 The Northern Ireland 2001 Census was used to provide data in relation to ethnic communities.

3.9 Geographical Information System

3.10 Social Security data broken down by geographical area is provided by the Department for Social Development to the Northern Ireland Statistics and Research Agency (NISRA) on an annual basis. The Geographical

Information System Unit (GIS) within NISRA provides access to this information via a web-based dissemination tool.

3.11 Table 1: Summary of Data Source by Equality Group

Equality Group	Source of Data
Men and Women Generally	Northern Ireland 1991 Census
Persons of different marital status	Northern Ireland 1991 Census Small Area Statistics
Persons with different Religious beliefs	Northern Ireland 1991 Census Small Area Statistics
Persons with/without Dependants	Northern Ireland 1991 Census Small Area Statistics
Persons of different sexual orientation	No data available
People of Different Ages	Noble Dataset 2000 Estimate (Northern Ireland Measure of Deprivation)
Persons of Different Political Belief	First Preference votes for seats won in June 2001 District Council Elections
Persons with/without a Disability	Northern Ireland 1991 Census Small Area Statistics* Social Security (GIS) as at March 2000
Persons from Different Racial Backgrounds	Northern Ireland 2001 census

*Proxy used - The aggregate of attendance allowance and incapacity benefit claimants was used as a proxy for those with/without a disability. However, as there may be issues surrounding the take-up of social security benefits, an alternative disability proxy was created based on numbers of people self-reporting a limiting long term illness at the 1991 Census of Population.

- 3.12 In general, data was obtained at ward level in respect of the majority of the nine equality groups (or suitable proxies for the groups). Unfortunately, no detailed information was available on sexual orientation and only Local Government District (LGD) data from the 2001 Census could be used for ethnic group.
- 3.13 Data on political preference was obtained at LGD level from first preference votes for seats won at the June 2001 Local Government elections (the Electoral Office does not have data in respect of the votes cast for individual electoral wards).

4 ACCESS TO CLINICAL GENETIC SERVICES

4.1 General access to services

4.2 Genetic disorders can affect all body systems and age groups. The aim of genetic services is to help those affected by, or at risk of, a genetic disorder to live and make informed decisions regarding reproduction in the context of associated risk of having offspring affected by genetically inherited disease.

4.3 Specialist genetics services can be distinguished from other medical services by the fact that they deal with families, often over several generations, and that they can provide genetic expertise for any age group affected by, or at risk of, disorders in any body system. Furthermore, genetic services are almost entirely outpatient based, unlike other medical specialties for which there are designated inpatient beds.

4.4 In addition, a large number of individuals with birth defects and/or learning disabilities are referred and investigated for genetic factors. Individuals identified through childhood or pregnancy screening programmes also require genetic services.

4.5 Service configuration

4.6 The Review's recommendations do not propose to change the current configuration of clinical genetic services, which are provided mainly from the Regional Genetics Centre at Belfast City Hospital and some local clinics. Nevertheless, equality impact assessments were carried out on access to the Regional Genetics Centre and also to clinical genetic services in the current configurations under the following sub-specialties:

- cancer genetics;
- general genetics, including children's services; and
- prenatal diagnostic.

4.7 **Access to services - general methodology**

4.8 Access times from the centre of each enumeration district (ED) to the various configurations of clinics was calculated using the software called SMOSS (Simplified Modelling of Spatial Systems), which was developed by Tony Hindle to inform a rurality adjustment in the Health and Social Services Boards' capitation formula, and was subsequently adapted for the Northern Ireland Ambulance Service Strategic Review. The lowest access time (ie time to the nearest clinic) for each ED was chosen. These were combined to produce an access time from each electoral ward by calculating an average weighted by the population of each ED within the ward. The access times were then divided into four ranges of access times ie 0-30 minutes, 30-60 minutes, 60 – 90 minutes and over 90 minutes.

4.9 ACCESS TO THE REGIONAL GENETICS CENTRE

4.10 An equality impact assessment was carried out on access to the Regional Genetics Centre at Belfast City Hospital, where the majority of genetics services are provided. The results are as follows.

4.11 **Between men and women generally:**

No evidence of adverse impact.

4.12 **Persons of different age:**

No evidence of adverse impact.

4.13 **Persons with or without a disability:**

No evidence of adverse impact.

4.14 **Persons of different marital status:**

No evidence of adverse impact.

4.15 **Persons of different religious belief:**

Potential adverse impact.

4.16 Roman Catholics appear to be under-represented in the range closest to services (26% compared to the Northern Ireland average of 38%) and over-represented in the ranges of higher access times, particularly in the “90 minutes and over range” (63%). This picture of potential negative impact on Roman Catholics is borne out by Table 2 below, which shows that over half of Protestants (58%) are less than 30 minutes from services compared to a third of Roman Catholics (33%). However, the data also shows that the majority of Roman Catholics (62%) are within 60 minutes from services, which may lessen the negative impact. As each access time range does not contain the same number of people, it is also helpful to look at the proportion of each religion in each range.

Table 2: Proportions of each religion in each range of access times

Access time (mins)	Religion			
	Roman Catholic	Protestant	Other	None/Not stated
0 to 30	33%	58%	60%	62%
30 to 60	29%	22%	25%	21%
60 to 90	18%	12%	10%	10%
90 and over	21%	8%	6%	7%
NI	100%	100%	100%	100%

4.17 Persons with/without dependants:

Potential adverse impact.

4.18 An analysis of available data also indicates a potential negative impact on the Dependants group with greater proportions of households with dependants further away from services.

4.19 Persons of different political opinion:

Potential adverse impact.

4.20 As regards Political Opinion, an analysis of data shows that Nationalists appear to be under-represented in those areas closest to services (27% compared to the Northern Ireland average of 42%) and over-represented in those areas farther from services (71% compared to the Northern Ireland average of 42%). This potential negative impact on Nationalists is confirmed by examining the proportions of each political grouping in each range of access times. It was found that half of all Unionists (50%), compared to just over a quarter of all Nationalists (26%), are less than 30 minutes from services. However, as this analysis was done at LGD level, it is somewhat crude and requires data at a lower level to be more conclusive.

4.21 Persons of a different racial group:

Potential adverse impact.

4.22 An analysis by Ethnic Group had also to be done at LGD level due to data constraints. Analysing the ethnic group composition of each time range is not very informative as it is generally 99% “white”. The analysis of data shows that Irish Travellers are noticeably further from services than other ethnic

groups (24% within 30 minutes of services) yet it is known that the travelling community have a good uptake of genetics services. The percentage of the ‘Other Black’ ethnic group (38%) within 30 minutes of services is also lower than other groups, which range from 45% (white) to 81% (Bangladeshi). However, it will be seen from the table below that the numbers in the two communities affected are relatively small. Also, a lower level analysis would be necessary to make a more conclusive judgement on a potential negative impact on these ethnic groups.

Table 3: Numbers of each ethnic group in each range of access times

Access Time (mins)	Ethnic Group											
	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla-deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
0 to 30	760,028	402	1,822	852	387	207	153	148	324	145	2,855	837
30 to 60	500,878	783	761	272	210	29	18	50	79	97	736	258
60 to 90	210,712	215	320	176	26	6	15	24	37	98	354	112
90 and over	199,370	310	416	267	42	14	13	34	52	44	200	83
	1,670,988	1,710	3,319	1,567	665	256	199	256	492	384	4,145	1,290

4.23 Persons of different sexual orientation:

No data available.

4.24 Conclusion

4.25 In general, it is noted that the location of the centralised Regional Genetics Clinic in Belfast appears to disadvantage Roman Catholics and Nationalists in relation to travelling times. However, it is to be noted that the majority of Roman Catholics are within the first two travel time bands (0-30 minutes and 30-60 minutes), which may lessen the potential negative impact.

Nevertheless, it will be necessary for equality aspects, and accessibility to services in particular, to be kept under review. In this regard, the Department will monitor access to clinical genetics services for adverse impact in the future.

4.26 ACCESS TO CANCER GENETICS CLINICS

4.27 Familial cancers are a major group of genetically inherited diseases. One in twenty cases of common cancers of the bowel, breast and ovary are due to mutant genes of high penetration. Carriers of these genes may have up to a 60-80% risk of developing the disease during their lifetime.

4.28 The cancer centre at Belfast City Hospital provides specialist clinical genetic services in partnership with the Regional Genetics Centre at the same site. The cancer units at Altnagelvin, Antrim, Belfast City, Craigavon, and the Ulster Hospitals offer cancer genetic services which are provided by staff at the Regional Genetics Centre. An impact assessment has been carried out on access to cancer genetic services using the current configuration of services outlined above. An analysis of the results is as follows.

4.29 Between men and women generally:

No evidence of adverse impact.

4.30 Persons of different age:

No evidence of adverse impact.

4.31 Persons with or without a disability:

No evidence of adverse impact.

4.32 Persons of different marital status:

No evidence of adverse impact.

4.32 Persons of different religious belief:

Potential adverse impact.

4.33 Roman Catholics appear to be under-represented in the range closest to services (32% for '0 to 30 minutes' compared to Northern Ireland average of

38%) and over-represented in those ranges farther from services especially in the ‘90 minutes and over’ range (70%).

Table4: Proportions of each religion in each range of access times

Access time (mins)	Religion			
	Roman Catholic	Protestant	Other	None/Not stated
0 to 30	58%	78%	79%	79%
30 to 60	35%	18%	18%	18%
60 to 90	5%	3%	3%	2%
90 and over	2%	1%	0%	1%
NI	100%	100%	100%	100%

Table 4 shows that over three quarters of all Protestants (78%) and just over half of all Roman Catholics (58%) are within 30 minutes of cancer genetic services. This confirms the impression given above that this configuration may have a potential negative impact on Roman Catholics.

4.34 Persons with/without dependants:

No evidence of adverse impact.

4.35 Persons of different political opinion:

Potential adverse impact.

4.36 Nationalists are under-represented in areas closest to services and over-represented in those areas farther from services. This potential negative impact on Nationalists is confirmed by the table below which shows three-quarters of Unionists (75%) compared to just over half of Nationalists (56%) are within 30 minutes of cancer genetic services. However, it is also of note that the majority of both Unionists (97%) and Nationalists (94%) are within 60 minutes from cancer genetics services, which may lessen the potential negative impact.

Table 5: Proportions of each political grouping in each range of access times

Access Time	Politics		
	Unionist	Nationalist	Other
0 to 30	75%	56%	81%
30 to 60	22%	38%	17%
60 to 90	0%	0%	0%
90 and over	3%	6%	1%
NI	100%	100%	100%

4.37 However, as this analysis is done at LGD level it is somewhat crude and requires data at a lower level to be more conclusive.

4.38 Persons of a different racial group:

Potential adverse impact.

4.39 The table below shows the proportions of each ethnic group in each range of access times. It shows that Irish Travellers are generally further from services than other ethnic groups.

Table 6: Proportions of each ethnic group in each range of access times

Access Time (mins)	Ethnic Group											
	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla-deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
0 to 30	70%	62%	77%	79%	89%	93%	88%	79%	83%	77%	84%	84%
30 to 60	26%	33%	20%	19%	10%	6%	9%	20%	14%	19%	15%	14%
60 to 90	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
90 and over	3%	5%	3%	1%	2%	2%	3%	1%	3%	5%	1%	2%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

4.40 Table 7 gives the actual number of people involved and it can be seen there are only 642 Irish Travellers out of a total population of 1,710 over 30 minutes from services. Also, a lower level analysis would be necessary to make a more conclusive judgement on a potential negative impact on this ethnic group.

Table 7: Numbers of each ethnic group in each range of access times

Access Time (mins)	Ethnic Group											
	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla-deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
0 to 30	1,176,967	1,068	2,558	1,241	589	237	176	201	410	294	3,491	1,087
30 to 60	436,825	556	664	305	65	15	18	52	67	72	607	178
60 to 90	0	0	0	0	0	0	0	0	0	0	0	0
90 and over	57,196	86	97	21	11	4	5	3	15	18	47	25
	1,670,988	1,710	3,319	1,567	665	256	199	256	492	384	4,145	1,290

4.41 Persons of different sexual orientation:

No data available.

4.42 Conclusion

4.43 In general, it is noted that the location of the cancer genetics clinics appear to disadvantage Roman Catholics, Nationalists and the Travelling community in relation to travelling times. It will, therefore, be necessary for equality aspects, and accessibility to services in particular, to be kept under review. In this regard, the Department will monitor access to cancer genetics services for adverse impact in the future. A recent development has been the holding of some cancer genetics clinics at the Erne Hospital, although this is not a cancer unit, solely to address the issue of travelling times.

4.44 ACCESS TO GENERAL CLINICAL GENETICS SERVICES

4.45 Referrals to the general clinical genetics service may include single gene disorders for adults and children of all ages, learning disability, visual and hearing difficulties and other puzzling problems.

4.46 An impact assessment was carried out on outpatient access to general genetic services, for adults and children, using the current configuration at the Belfast City Hospital, the Royal Belfast Hospital for Sick Children, Cupar Street Clinic (Belfast), Antrim Hospital, Altnagelvin Hospital, Bridgeview Clinic at Stradreagh Hospital in Derry, Erne Hospital and Craigavon Area Hospital, which incorporates the Child Development Clinic at Lurgan.

4.47 Between men and women generally:

No evidence of adverse impact.

4.48 Persons of different age:

No evidence of adverse impact.

4.49 Persons with or without a disability:

No evidence of adverse impact.

4.50 Persons of different marital status:

No evidence of adverse impact.

4.51 Persons of different religious belief:

Potential adverse impact.

4.52 There would appear to be an under-representation of Roman Catholics in the range closest to services (33% for '0 to 30 minutes' compared to the Northern Ireland average of 38%) and an over-representation in those ranges farther from services (54% in the '30 to 60 minutes' range and 52% in the '60 to 90

minutes' range). A similar picture emerges when the proportion of each religion in each range is analysed (see Table 8 below).

Table8: Proportions of each religion in each range of access times

Access time (mins)	Religion			
	Roman Catholic	Protestant	Other	None/Not stated
0 to 30	64%	81%	82%	81%
30 to 60	35%	19%	18%	19%
60 to 90	1%	0%	0%	0%
90 and over	0%	0%	0%	0%
NI	100%	100%	100%	100%

4.53 Table 8 shows that 81% of Protestants compared to 64% of Roman Catholics are within 30 minutes of services. This confirms the impression given above that this configuration may have a negative impact on Roman Catholics. However, Table 8 also shows that the majority of Roman Catholics (99%) and Protestants (100%) are within 60 minutes from services. This may lessen the potential negative impact overall.

4.54 Persons with/without dependants:

No evidence of adverse impact.

4.55 Persons of different political opinion:

Potential adverse impact.

4.56 As regards Political Opinion, data shows that Nationalists appear to be under-represented in those areas closest to services (37% compared to the Northern Ireland average of 42%) and over-represented in those areas farther from services (57% compared to the Northern Ireland average of 42%). An analysis of the proportions of each political grouping in each range of access times shows that 78% of Unionists, compared to 62% of Nationalists, are within 30 minutes of general genetic services. This confirms a potential negative impact on Nationalists. However, as this analysis is done at LGD level it is somewhat crude and requires data at a lower level to be more conclusive.

4.57 Persons of a different racial group:

Potential adverse impact.

4.58 Table 9 below shows the proportions of each ethnic group in each range of access times. It shows that Irish travellers are generally further from services than other ethnic groups.

Table 9: Proportions of each ethnic group in each range of access times

Access Time (mins)	Ethnic Group											
	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla-deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
0 to 30	74%	67%	80%	81%	90%	94%	91%	80%	86%	81%	85%	86%
30 to 60	26%	33%	20%	19%	10%	6%	9%	20%	14%	19%	15%	14%
60 to 90	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
90 and over	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

4.59 As can be seen in Table 10 below, the numbers of people involved are relatively small with only 556 out of a total population of 1,710 over 30 minutes from services. Also, a lower level analysis would be necessary to make a more conclusive judgement on a potential negative impact on this ethnic group.

Table 10: Numbers of each ethnic group in each range of access times

Access Time (mins)	Ethnic Group											
	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla-deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
0 to 30	1,234,163	1,154	2,655	1,262	600	241	181	204	425	312	3,538	1,112
30 to 60	436,825	556	664	305	65	15	18	52	67	72	607	178
60 to 90	0	0	0	0	0	0	0	0	0	0	0	0
90 and over	0	0	0	0	0	0	0	0	0	0	0	0
	1,670,988	1,710	3,319	1,567	665	256	199	256	492	384	4,145	1,290

4.60 Persons of different sexual orientation:

No data available.

4.61 Conclusion

4.62 In general, it is noted that the location of the general clinical genetics clinics appear to disadvantage Roman Catholics, Nationalists and the Travelling

community in relation to travelling times. It will, therefore, be necessary for equality aspects, and accessibility to services in particular, to be kept under review. In this regard, the Department will monitor access to clinical genetics services for adverse impact in the future.

4.63 ACCESS TO PRENATAL DIAGNOSTIC GENETICS SERVICES

4.64 Pre-pregnancy genetic screening can identify carriers of serious inherited conditions such as cystic fibrosis and enable reproductive choices to be made such as prenatal or pre-implantation diagnosis, sperm or egg donation, avoidance of pregnancy, or adoption. Antenatal screening can be carried out for a number of genetic disorders including chromosomal abnormalities, which cause birth defects such as mental retardation (Down's syndrome), neural tube defects and cleft lip and palate.

4.65 The Regional Genetics Centre holds two prenatal diagnostic clinics jointly with obstetricians in the Royal Jubilee Maternity Hospital every week. A prenatal diagnosis clinic is also held weekly in Antrim Hospital.

4.66 An impact assessment was also carried out on access to prenatal diagnostic services using the current service configurations at the Royal Jubilee Maternity Hospital and Antrim Hospital.

4.67 Between men and women generally:

No evidence of adverse impact.

4.68 Persons of different age:

No evidence of adverse impact.

4.69 Persons with or without a disability:

No evidence of adverse impact.

4.70 Persons of different marital status:

No evidence of adverse impact.

4.71 Persons of different religious belief:

Potential adverse impact.

4.72 It would appear that Roman Catholics are under-represented in the range closest to services (26% compared to the Northern Ireland average of 38%) and over-represented in the ranges of higher access times, particularly in the ‘90 minutes and over’ range (62%). This picture of potential negative impact on Roman Catholics is borne out by Table 11 below which shows that almost two-thirds of Protestants (64%) are less than 30 minutes from services compared to around a third of Roman Catholics (36%).

Table 11: Proportions of each religion in each range of access times

Access time (mins)	Religion			
	Roman Catholic	Protestant	Other	None/Not stated
0 to 30	36%	64%	67%	66%
30 to 60	30%	21%	23%	20%
60 to 90	24%	10%	8%	10%
90 and over	9%	4%	3%	3%
NI	100%	100%	100%	100%

4.73 Persons with/without dependants:

Potential adverse impact.

4.74 There is a potential negative impact on the Dependants group with a greater proportion of households with dependants located further away from prenatal genetics clinics (62% of households with dependants as opposed to 38% of households without dependants in both the “60 – 90 minutes and over 90 minutes” categories, compared to 57% of households with dependants at a Northern Ireland level).

4.75 Persons of different political opinion:

Potential evidence of adverse impact.

4.76 As regards Political Opinion, Table 12 shows that Nationalists appear to be under-represented in those areas closest to services (26% compared to the Northern Ireland average of 42%) and over-represented in those areas farther from services.

Table 12: Political Opinion Composition of access time ranges

Access Time	Politics		
	Unionist	Nationalist	Other
0 to 30	59%	26%	15%
30 to 60	45%	50%	5%
60 to 90	25%	71%	4%
90 and over	35%	63%	2%
NI	48%	42%	9%

4.77 Persons of a different racial group:

Potential adverse impact.

4.78 An analysis of available data shows that Irish Travellers are noticeably further from services than other ethnic groups with only 28% within 30 minutes of prenatal genetic clinics. The percentage of the “Other Black” ethnic group (41%) is also lower than the other groups for access to services within 30 minutes.

4.79 However, it will be seen from the table below that the numbers in the two communities affected are relatively small. Also, a lower level analysis would be necessary to make a more conclusive judgement on a potential negative impact on these ethnic groups.

Table 13: Numbers of each ethnic group in each range of access times

Access Time (mins)	Ethnic Group											
	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla-deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
0 to 30	818,233	476	1,911	890	423	211	158	148	340	156	2,947	876
30 to 60	573,584	783	885	349	191	31	25	63	85	102	922	264
60 to 90	183,921	312	362	266	37	10	8	39	49	102	219	114
90 and over	95,250	139	161	62	14	4	8	6	18	24	57	36
	1,670,988	1,710	3,319	1,567	665	256	199	256	492	384	4,145	1,290

4.80 Persons of different sexual orientation:

No data available.

4.81 Conclusion – prenatal genetics clinics

- 4.82 Pre-natal diagnostic genetics screening services have tended to be concentrated in Belfast where specialist expertise is readily available to provide high quality, affordable services. The establishment of the weekly pre-natal diagnostic clinic in Antrim has helped to improve accessibility of these specialist services for some people.
- 4.83 In general, it is noted that the location of the prenatal diagnostic genetics clinics appear to disadvantage Roman Catholics, Nationalists, the Travelling community and “Other Black” ethnic groups in relation to travelling times. It will, therefore, be necessary for equality aspects, and accessibility to services in particular, to be kept under review. In this regard, the Department will monitor access to clinical genetics services for adverse impact in the future.

4.84 OVERALL CONCLUSION ON ACCESS TO SERVICES

- 4.85 Clinical genetics is a highly specialised area which requires services to be provided on a regional basis. The Review of Genetic Services does not propose to change the existing service configuration. However, although services are predominantly provided at the Belfast City Hospital site, clinics are also held locally to help promote accessibility. The local clinics have been located in areas where the demand is greatest as genetic conditions are not necessarily equally spread throughout geographical areas.
- 4.86 Whilst certain ethnic groups, including the travelling community, have a higher incidence of genetic disorders, it should be noted that there is a good uptake of services by travellers.
- 4.87 A summary of the data analysis for all four service configurations shows the following results:

Table 14- Summary of Equality Analysis for all service configurations

Equality Group	Regional Genetics Centre	Cancer Genetics Clinics	General Genetics Clinics	Prenatal Genetics Clinics
Gender	N	N	N	N
Age	N	N	N	N
Marital Status	N	N	N	N
Disability	N	N	N	N
Religious Belief	P	P	P	P
Dependants	P	N	N	P
Political Opinion	P	P	P	P
Ethnic Group	P	P	P	P

N = No differential Impact

P = Potential Impact

No data available for persons of different sexual orientation

- 4.88 Under all four configurations, there is evidence of more than expected Roman Catholics, Nationalists and Ethnic Groups further away from services. To some extent, this impact may be mitigated by the fact that lower income groups may qualify for travelling expenses to hospital. There is also some

evidence that Homes with Dependants are further away from the Regional Genetics Centre and Prenatal Diagnostic Genetics Clinics than Homes without Dependants.

- 4.89 It will, therefore, be necessary for equality aspects, and accessibility to services in particular, to be kept under review. In this regard, the Department will monitor access to clinical genetics services for adverse impact in the future.

HUMAN RIGHTS ACT

5.1 The Human Rights Act 1998 is an Act of the Westminster Parliament and came into force on 2 October 2000. The Act has the effect of incorporating the European Convention on Human Rights (ECHR) into domestic law.

5.2 **The Human Rights Act:**

- makes it unlawful for a public authority to act incompatibly with the Convention rights and allows for a case to be brought in a UK court or tribunal against the authority where it does so. However, a public authority will not have acted unlawfully under the Act if, as the result of a provision of primary legislation, it could not have acted differently.
- requires that all legislation be interpreted and given effect as far as possible compatibly with the Convention rights. Where it is not possible to do so, a court may:
 - quash or disapply subordinate legislation or
 - if it is a higher court, give a declaration of incompatibility for primary legislation thereby triggering a new power allowing a Minister to make a remedial order to amend the legislation to bring it into line with the Convention rights.
 - requires UK courts and tribunals to take account of the case-law of the Court and the Commission in Strasbourg and also the Committee of Ministers. They will also be bound to develop the common law compatibly with the Convention rights.

5.3 The European Convention on Human Rights is a treaty of the Council of Europe. The Council of Europe is an organisation of governments created in 1949 with the general aim of enhancing the cultural, social and political life

of Europe. It pre-dates and is quite separate from the European Union and the Convention is distinct from the general code of European Union law.

5.4 The Convention was adopted in 1950 and ratified by the Westminster Parliament in 1951.

5.5 The Convention guarantees the following rights and freedoms:

- The right to life
- The right to freedom from torture and inhuman or degrading treatment or punishment
- The right to freedom from slavery, servitude and forced or compulsory labour
- The right to liberty and security of person
- The right to a fair and public trial within a reasonable time
- The right to freedom from retrospective criminal law and no punishment without law
- The right to respect for private and family life, home and correspondence
- The right to freedom of thought, conscience and religion
- The right to freedom of expression
- The right to freedom of assembly and association
- The right to marry and found a family
- The prohibition of discrimination in the enjoyment of the convention rights
- The right to access to education
- The right to free elections
- The right not to be subjected to the death penalty

5.6 All public authorities have a positive obligation to ensure that respect for human rights is at the core of their day to day work. The Human Rights Act underpins this by making it unlawful for a public authority to act (or fail to act) in a way which is incompatible with a Convention right.

5.7 In order to fulfil this obligation and ensure that clinical genetics policy is compatible with the Convention rights, this Equality Impact Assessment has also considered the proposals made by the Clinical Genetic Services Review and the potential impact they may have on the Convention rights and freedoms outlined above.

5.8 In light of this assessment, the Department has determined that none of the proposals are incompatible with the Convention rights.

6 **CONCLUSION**

- 6.1 This equality impact assessment (EQIA) addresses the Department's proposals for taking forward the Future Development of Clinical Genetic Services. The Clinical Genetic Services Review is intended to address the needs of clinical genetics services over the next 5 - 10 years. The findings are based on the information available and the best estimates of future demand. The proposed further expansion of the genetics service will have a positive effect on clinical genetics services by further increasing the quality and speed of access to genetics services.

- 6.2 As outlined in Chapter 4, it will be necessary for equality aspects to be kept under review. In this regard, the Department will monitor access to clinical genetics services for adverse impact in the future.