

Equality Action Plan 2013-18

A report of the Consultation Feedback

August 2013

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Introduction

This is a report of the consultation feedback we received in relation to our Section 75 equality duties specifically the review of our Equality Action Plan. Our first action plan looking at what we could do differently to target inequalities and promote equality of opportunities across any of the 9 equality categories was in place until March 2013.

In our Equality Scheme we gave a commitment to monitoring progress and updating the plan as necessary. We also said we would engage and consult with stakeholders when reviewing the action plan.

We work closely with the Business Services Organisation and a range of Health and Social Care partner organisations on equality matters.

During the autumn 2012 each organisation listed in Table 1 undertook an internal review. With help from the Equality Unit in the Business Services Organisation we launched our 5 year action plans (2013-2018) for a joint public consultation, in the main between December 2012 and March 2013.

Table 1 List of organisations that reviewed their equality action plans

Blood Transfusion Service	www.nibts.org
Business Services Organisation	www.hscbusiness.hscni.net
Health and Social Care Board	www.hscboard.hscni.net
NI Guardian Ad Litem Agency	www.nigala.hscni.net
NI Practice and Education Council for Nursing and Midwifery	www.nipec.hscni.net
Northern Ireland Social Care Council	www.niscc.info
Patient and Client Council	www.patientclientcouncil.hscni.net
Public Health Agency (PHA)	www.publichealth.hscni.net
Regulation and Quality Improvement Authority	www.rqia.org.uk

Thank you to those who responded

We would like to take this opportunity to say thank you to consultees who took the time to respond to this consultation exercise.

Organisations who responded

Table 2 outlines the organisations who responded with comments. In some instances these were targeted at specific organisations whilst in others the comments were generic. Table 3 presents the generic comments received and our responses. It also shows the specific issues which were raised with the Public Health Agency (PHA) and our responses to these. We hope that the responses provided in Table 3 reflect the views and comments raised and that our responses provide the necessary detail to better understand how we have considered any issues raised.

Table 2 Organisations who responded

Name of organisation	Type of response
*Disability Action	Detailed comments to all organisations listed in Table 1 and some specific comments to the Business Services Organisation
Northern Ireland Rare Disease Partnership	Detailed comments to the PHA and the Health and Social Care Board only
Carol McCullough	Detailed comments to the PHA only

*Disability Action targeted responses to each of the organisations listed in Table 1. An analysis of the comments revealed that these were in the main generic and targeted at all organisations (except for the HSC Board). A decision was taken to provide one consultation feedback table for these.

The eight organisations who did not receive any additional submissions specific to them have published a joint consultation report.

In the review of their plans each organisation however considered both generic and specific comments raised.

Table 3 Equality Action Plans - Comments made by consultees and responses

Consultee Comment	Response
Disability Action	
<p>Disability Action is disappointed that the Audit of Inequalities has not accompanied this Equality Scheme and Action Plan. The Audit of Inequalities is a systematic review and analysis of inequalities which exist for service users and those affected by the Organisation’s policies. The audit should include analysis of information gathered to inform the development of an Action Plan. The absence of the Audit of Inequalities renders it impossible for the consultee to understand the rationale for measures in or omitted from the Action Plan.</p>	<p>During 2012-2011 organisations carried out major audit of inequalities in order to produce 2 year equality action plans</p> <p>The Action Plan produced for the period 2013-2018 reflects a review and update of the 2011-2013 plan. In its development consideration was given to a review of priorities and consideration of new priorities.</p> <p>An additional audit of inequalities was not undertaken.</p> <p>To clarify this, an explanatory paragraph has been added to the document.</p>
<p>Disability Action believes that the organisation should state that the audit of inequalities is a “living” document that will be amended as continued evidence is gathered on newly identified inequalities.</p>	<p>The nature of the plan in that it is reviewed on an annual basis determines that it is in fact a living document. This has been clarified in the preamble.</p>

<p>Where the audit of inequalities has identified information or evidence of gaps the Organisation must commit to commission new research.</p>	<p>We have limited capacity at this stage to commission new research but we acknowledge the contribution made by other organisations in this respect.</p> <p>In some cases if relevant, research will be conducted, such as in relation to lesbian, gay, bisexual, and transgender issues.</p>
<p>Audit of Inequalities (by Disability Action)</p>	
<ul style="list-style-type: none"> • The audit does not provide a clear link to the organisation’s actual functions, policy areas and strategies. • The organisation must clearly show how it has utilised the consultation responses provided by Section 75 representative groups and affected individuals over the past 10 years on equality schemes/screening and EQIAs. It must clearly show how it used qualitative and quantitative data held by other public authorities. 	<p>We have attempted in this action plan to produce an easier to understand document outlining in jargon free language what our organisation does.</p> <p>In the contents page precise actions across a range of business functions are now listed.</p> <p>This was a “review exercise”. Its development was informed by a number of sources of information including:</p> <ul style="list-style-type: none"> • 2010-11 Audit of Inequalities completed templates or notes by service area • Consideration on any equality issues emerged since 2010-2011 • new research undertaken by other organisations new data, both quantitative and qualitative having become available

<ul style="list-style-type: none"> • All the relevant qualitative and quantitative data that was used as well as findings for each Section 75 category must be provided to consultees. • Data, research, evidence and publications must be set out under each of the 9 categories listed under Section 75. • The organisation must provide a clear audit trail not a literature review with no findings. • A gap analysis should have been undertaken. 	<p>new equality screening exercises having been completed issues raised in consultations or through other engagement with staff and service users.</p> <p>The BSO's Equality Unit collate and provide evidence on their website from recent research, statistical studies, Census report and other documents.</p> <p>This "Information Bank" relates to all of the Section 75 categories and includes issues in relation to disability duties. This is available on: http://www.hscbusiness.hscni.net/services/1798.htm</p> <p>Likewise our equality screening reports which also document the evidence for the purposes of screening are published quarterly http://www.hscbusiness.hscni.net/services/2246.htm</p> <p>Unclear what this point actually means in context of reviewed action plan.</p> <p>In terms of gaps in information and systems our current review of information systems is one attempt to identify current gaps in</p>
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<ul style="list-style-type: none"> • The Audit of Inequalities should clearly outline any gaps in its knowledge and detail how these gaps will be filled, for example, provide details of the specific commissioned research necessary to fill these gaps. • Audit findings must be cross-referenced to each measure within the Action Plan. • The organisation should clearly show how the Audit of Inequalities will be used to 	<p>information.</p> <p>The recent Census 2011 has been a useful source of contemporary quantitative data and is currently utilised to support the equality agenda.</p> <p>Gaps in data are an acknowledged issue within the organisation. Some specific actions relate to monitoring to facilitate better collection of equality data.</p> <p>The BSO provides human resources support to a range of health and care organisations with Human Resources functions and is committed to introducing a new Human Resources Information System (Human Resources, Payroll, Travel and Subsistence). As part of the roll out of this staff will be prompted to complete equality monitoring records which address any gaps in data relating to employment.</p> <p>As previously noted this action plan is a review of the previous action plan rather than an additional audit of inequalities. The relevant inequality is described for each theme in the Action Plan.</p> <p>In the on-going screening exercises evidence collated as part of the first tranche of audits of inequalities have, where relevant,</p>
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<p>inform the screening process. Data collected must be used to inform future screening and EQIA's.</p> <ul style="list-style-type: none"> • There should be information on how the Audit of Inequalities informs the Organisation's necessary resource allocation in terms of people, time and money. • Absence of evidence must not mean that acknowledged inequalities are ignored. There is an opportunity to tackle entrenched and persistent inequalities faced by disabled people. • Data on inequalities must be collected across both Duties1 and 2 of Section 75 of the Northern Ireland Act 1998. 	<p>been used alongside more up to date evidence. Some of the actions identified may in themselves be subject to further equality screening.</p> <p>The previous audit and equality screening outcomes constitutes one source of information taken into consideration, alongside other data, in the allocation of resources.</p> <p>Comment noted. This key requirement is communicated to all staff in equality screening sessions.</p> <p>Comment noted.</p>
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<ul style="list-style-type: none">• Disability Action expects an audit of inequalities to be a robust analysis of all 9 Section 75 categories, in particular for disabled people, across all functions and policy areas. Failure to do so will render the Action Plan fundamentally flawed.	<p>As indicated previously the exercise in 2012-2013 was a review exercise which built on previous work. In terms of cost effectiveness however the organisation also needed to exercise some pragmatism in prioritising actions to be taken across diverse function areas. Where relevant and feasible issues in relation to disability categories are included in the action plan. Further targeted actions are included in the Disability Action Plan for 2013-2018.</p> <p>It is important to highlight that the Equality Action Plan is intended to reflect some priority areas where the organisations can make a difference, not all areas of equality activity.</p> <p>Other mainstream activity particularly screening of policies supports the wider agenda.</p>
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Action Plan (by Disability Action)	
<ul style="list-style-type: none"> • Action measures should be clearly linked to the functions of the organisation. This is not the case. • A cross reference of the Organisation’s audit findings and their link to action measures should be included for ease of reference. • Action measures must be clearly specific to each of the 9 affected groups listed under Section 75. Multiple identity action measures must also be clearly specified across the 9 categories. • An Action Plan should detail whether measures are new or on-going action. This Plan does not provide such detail. • Clear indication if actions are new as a direct result of the audit of inequalities. The organisation’s Action Plan must include measures to address any gaps identified. 	<p>Contents page now outlines the action measures across the functions of the organisation.</p> <p>As previously noted this was a review exercise, an additional audit of inequalities was not undertaken. Wherever possible the underlying inequality has been referenced.</p> <p>The action measures identified are targeted at specific equality categories and in some instances, where relevant, multiple inequalities are addressed.</p> <p>This has now been addressed in the contents page to the new action plan.</p> <p>Actions in this action plan build on or are, in some instances, new actions. They were developed in response to the organisation’s initial audit of inequalities conducted in 2010-2011 and subsequent prioritisation of actions.</p> <p>Responses to previous points raised explain how the review of this action plan was undertaken.</p>

<ul style="list-style-type: none"> • The collection of qualitative and quantitative data, on the gaps, must be an action measure in each subsequent year. • Information must be provided on how the Action Plan measures were prioritised. • The Action Plan must contain SMART objectives including a timetable with expected outputs and outcomes. • Timetables must relate to achieving outcomes and not implementation dates which reflect the beginning of a process. • The review of the audit of inequalities must be an action measure. Monitoring and evaluation must be an action measure. 	<p>Comment noted</p> <p>Action measures were prioritised in respect of, mainstreaming, potential benefits, risk of not taking action, importance for the business of our organisations and scope within the function area to make a difference within the timescale and resources.</p> <p>Comment noted. We believe objectives and timelines set are based on a realistic view when actions and outcome can be realised.</p> <p>Comment noted. The annual review of progress will allow for dialogue on longer term outcomes.</p> <p>Comment noted. Inequalities will be kept under review on a regular basis as part of annual reviews within the lifetime of the plan and at the end of the plan in its 5 year review. Monitoring of the delivery of actions in the plan will take place as part of the Section 75 reporting requirements to the Equality Commission.</p>
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<ul style="list-style-type: none"> • A full review of the Action Plan after 1 year should be included as an action measure. • The Plan should include a clear outline of how the Action Plan interacts with Corporate and Business Planning measures. • Action measures related to the Organisation's strategic as well as operational functions should be included. • The Organisation must make clear that the Action Plan is a living document that can be added to and amended as other inequalities are identified. • A Clear statement on whether action measures are relevant to Duties 1 and 2 of Section 75 should be included. 	<p>Reference to this has been made in the preamble which refers to the fact that an annual review is already required as part of Equality Commission's reporting. Consequently a precise action in the action plan is not included as it does not add any further value</p> <p>Now included in the introduction.</p> <p>A range of actions are included that relate to both strategic and operational functions.</p> <p>The nature of the action plan in that it is reviewed on an annual basis determines that it is in fact a living document.</p> <p>This has already been highlighted in the introduction to the action plan.</p> <p>Clarity has been provided in the revised plan.</p>
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<ul style="list-style-type: none"> • The Organisation must not concentrate only on the Action Plan measures to the detriment of its Section 75 obligations in terms of other functions and policy areas and newly emerging inequalities. 	<p>The Organisation continues to review all its Section 75 Equality duties in relation to, for example, training, communications, screening and consultations. Regular reporting, within the organisation and externally, including to the Equality Commission highlights on-going progress in this area.</p>
<ul style="list-style-type: none"> • Actions should be grouped across 9 Section 75 groups. 	<p>Given the diversity of the functions of the organisation and how it operates a decision was taken to present the action plan by function rather than equality category. Consideration will be given to this in reports to the Equality Commission where impacts by category will be highlighted.</p>

Northern Ireland Rare Disease Partnership (Specific comments directed at the Public Health Agency only)	PHA response
<p>Rare diseases are not a minority issue</p> <ul style="list-style-type: none"> • Disease is “rare” if it affects fewer than 5 people per 10,000. • There are over 6,000 rare diseases, with others being defined all the time. • One in 17 people is likely to be affected by a rare disease at some point in their lives; that is almost 106,000 people in Northern Ireland 	<p>Information is noted</p>
<p>International recognition of needs for improvement in rare diseases standards of care</p> <ul style="list-style-type: none"> • Health 2020 project report underlined key problem of GPs missing or misdiagnosing rare diseases – suffering caused for years as a result of misdiagnosis and inadequate treatment • many professionals largely unaware of signs, symptoms or behaviours – much greater awareness is needed of the 	<p>In our role in supporting the Commissioning process we will bring this information to the attention of the Health and Social Care Board.</p>

<p>availability of pathways to specialist and expert centres</p> <ul style="list-style-type: none"> • without accurate diagnoses, the reliable information essential for efficient health and social care planning is simply not there; appropriate medical treatment is not made available; appropriate follow up care and support in the community is not made available • a diagnosis alone cannot ensure appropriate care and support in the community if those delivering care are not equipped to deal with protocols necessary for rare disease • we need a much better understanding of the extent to which inequalities exist 	
<p>PHA can be a driving force in resolving inequalities for those affected by rare disease</p>	<p>Comment is noted</p>
<p>Equality considerations</p> <ul style="list-style-type: none"> • those who have rare diseases, and those who care for them, are entitled to protection under the principles set out in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and 	<p>Comments are noted</p>

<p>the UN Convention on the Rights of the Child (UNCRC); those who have disability related to rare diseases, and those who care for them, are entitled to equality of opportunity in accordance with the Northern Ireland Act 1998: Section 75 and the Disability Discrimination legislation</p> <ul style="list-style-type: none"> • achieving the PHA’s aim “to promote equality of opportunity” for those affected by rare disease is only possible through sourcing much more information than is currently available, and through improvement in service provision for rare disease at all levels • role of the PHA is key to ensuring progress towards genuine equality for those impacted by rare diseases 	
<p>Combating existing challenges and inequalities of rare disease</p> <ul style="list-style-type: none"> • Whole systems approach is particularly necessary for rare diseases • We support a Human Rights Based Approach, that encompasses rare disease equality issues • Commissioning: We are aware that our 	<p>In our role in supporting the Commissioning process we will bring this information to the attention of the Health and Social Care Board.</p>

vision of care must complement analysis of need within population plans and go beyond an offering in its own right. However we would also wish to challenge any commissioning model where we simply respond to such an analysis, without considering different ways of service delivery. Our experience is that such a commissioning model has largely failed the needs of those with rare diseases, due in large part to the lack of information and opportunities for meaningful engagement, leading to a lack of awareness and understanding of need. We need commissioning that produces tangible change and redresses the balance of inequality in service provision for rare diseases. Greater diversity in the types of care must be developed.

- **Health and Social Policy:** those affected by rare disease are often marginalised and disadvantaged due simply to their condition being rare and largely misunderstood; there needs to be a much greater recognition that rare disease creates different needs,

experiences, issues and priorities in relation to policy and service delivery decisions. At present we feel that these aspects of rare disease are underrepresented in health and social policy. We feel strongly that rare diseases, and the specific issues they raise, should be explicitly referenced in the narrative accompanying the PHA Equality Action Plan and all relevant plans and strategies so that it is made clear proposals are fully inclusive of, and applicable to, all patients and carers, and not aimed simply at those affected by common conditions and diseases.

- **Research:** We recognise benefit of research into rare disease in promoting greater understanding of more common diseases. Without this research the continuing lack of knowledge, regarding diagnosis and appropriate treatment, will impact on equality of opportunity for those who are actually affected by rare disease. Currently very little research exists on the management of rare disease patients. A strategy for research and information is being developed.

An appendix has now been added to the Action Plan which lists examples of groups covered under the nine equality categories. Specific mention is made therein in respect of rare diseases that fall under the definition of a disability.

We will share this thinking with the Department of Health, Social Services and Public Safety, who are in the process of developing a new Research and Development Strategy for Health and Social Care in Northern Ireland.

Support for research into rare disease, particularly in the area of diagnosis and care of individuals with rare diseases, should be considered an essential area of development. It is also important that any research strategy should include consultation with those individuals with rare diseases in order to identify key areas for prioritisation.

- **Data collection and analysis:** We recommend that a registry of congenital anomalies separate or part of a registry of rare diseases should be promoted.
- **Raising Awareness Programmes:** there should be: (1) Recognition of those affected by rare disease as a distinct 'at risk' group; (2) Designation of rare disease as a priority area, alongside other major health issues; (3) Joint efforts to raise awareness of the blight of rare disease and related inequalities: initially, for example, a poster campaign targeted at HSC and educational establishments to raise awareness of rare diseases and warn of the risk of misdiagnosis. Targeted areas might include GP clinics; hospital outpatient

We will make the Department of Health, Social Services and Public Safety and the HSC Board aware of this recommendation.

The PHA is currently working with Huntingdon's Disease Association Northern Ireland (HDANI) on bringing in external experts to raise awareness amongst health care professionals in relation to Huntington's disease at a dedicated conference in September 2013.

The PHA are working with people living with or caring for those with a Neurological Condition, to commission the development of a generic training programme, that will raise awareness of issues and challenges faced by those with a Neurological Condition.

clinics and university campuses.

- **Personal and Public Involvement:** those who have rare diseases and their families often do not have the advantage of support groups or easy access to expert centres; are often very isolated
- **Education and Training:** evolution of a reliable and extensive knowledge base is essential; we are keen to see advances in graduate and postgraduate training to help alert clinical professionals to the possibility of a rare disease; and increase diagnostic skills and standards for ongoing treatment and management. We also feel it important that improvement in knowledge and skills in other professional areas such as Nursing; Allied Health Professionals; Social Work and GP Practice Managers is facilitated. We strongly support revision of Disability Awareness Training to include recognition of specific difficulties encountered by those who have a disability caused by rare disease and their families; including raising awareness of the isolation and stigma associated with rare disease, which

The PHA is commissioning research that will also examine the practical application of personal and public involvement methods to facilitate the involvement of marginalised and isolated patients and their families.

We will share this comment with the Northern Ireland Practice and Education Council for Nursing and Midwifery, the Chief Nursing Officer and the Department of Health, Social Services and Public Safety.

Under its Disability Action Plan, the Agency has committed to a programme of awareness raising for staff in relation to the wide range of disabilities. Specific consideration will be given to opportunities for highlighting issues related to rare diseases in this context.

impacts strongly on mental health

- **Delivery of Care:** 'shift left' needs to be accompanied by a 'shift right' to ensure access to specialist centres; essential are (1) greater awareness of the possibility of rare disease (2) increased use of ICT in sourcing information (3) access to guidance (4) availability of diagnostic techniques (5) improved coordination of care and recognised care pathways (6) faster access to supra specialised care (7) appropriate skills within multi-disciplinary teams and use of suitable care plans throughout continuing care
- **Rare Disease Coordinators:** vital role in managing services, providing advice and support to individuals and families, promoting education and training, raising public awareness of rare disease, facilitating use of technology, and facilitating access to reliable data – social workers and allied health professionals well placed for this (with training and experience)

In our role in supporting the Commissioning process we will bring this information to the attention of the Health and Social Care Board.

The HSCB and the PHA have identified non-recurrent funding to pilot two care advisor posts for people with Neurological Conditions. A number of people with Neurological Conditions also have rare diseases.

<p>PHA Equality Action Plan: Themes and Actions</p> <p>Proposals can have a significant impact in providing guidance to those working at the front line of service delivery</p>	<p>Comment is noted.</p>
<p>Theme 2: Cancer Screening</p> <p>Members of all groups listed can be affected by rare disease; therefore coexisting issues may compound inequalities and participation in cancer screening.</p> <p>We also believe that those who are affected by rare cancers, or common forms of cancer in combination with rare disease, may suffer additional inequalities due to lack of awareness, understanding and accessibility of services to support those affected by (a) rare cancers; or (b) the presence of comorbid conditions where rare disease and an additional illness is a factor thus increasing complexity of illnesses and necessary support.</p>	<p>Comment is noted.</p>
<p>Theme 3: Childhood Immunisation</p>	<p>Comment is noted.</p>

<p>Individuals from all at risk groups listed may suffer from, or may be a member of a family affected by, rare disease and therefore encounter additional inequalities related simply to the fact a disease is rare.</p> <p>We are pleased that recognition has been given to the significance of information on “at risk groups”; feedback in monitoring performance indicators and work to promote childhood immunisation within the migrant and Travelling communities.</p> <p>However we also need much greater feedback on rare disease than is currently available.</p>	
<p>Theme 4: Migrants</p> <p>Members of ethnic communities, who are already isolated, will suffer additional inequality of opportunity due to rare disease issues. We know that some communities e.g. Travellers, those of southern Mediterranean/sub Saharan areas origin, are at increased risk of some rare diseases. Innovative approaches, tailored to the culture and lifestyle of these groups are</p>	<p>Comment is noted.</p>

<p>needed to tackle these risks.</p>	
<p>Theme 5: Lesbian, Gay, Bisexual and Transgender</p> <p>inequality issues affecting LGB&T groups in relation to employment and services will be compounded by the additional presence of rare disease</p>	<p>Comment is noted</p>
<p>Theme 6: Personal and Public Involvement</p> <p>We strongly reinforce our belief in improvement in networking and building of relationships with: all those affected by rare disease who fall within categories of Section 75 of the Northern Ireland Act 1998; and representative organisations.</p>	<p>The PHA actively work with a wide range of stakeholders, including those affected by rare disease. At this time the PHA are supporting a project with the Rare Disease Partnership Northern Ireland (RDPNI), and the HSCB to identify the experiences of people living with a rare disease.</p>
<p>Theme 7: PHA as an employer</p> <p>We are keen that issues related to rare disease, including existing inequalities and challenges faced by those who are affected by rare disease, are included in all relevant PHA staff guidelines and disability</p>	<p>Under its Disability Action Plan, the Agency has committed to a programme of awareness raising for staff in relation to the wide range of disabilities. Specific consideration will be given to opportunities for highlighting issues related to rare diseases in this context.</p> <p>In its work with the BSO and partner organisations on guidance for line managers the Agency will recommend that reference is made</p>

<p>awareness training.</p> <p>We are keen that 'rare disease' is added to criteria in guidelines supporting at risk staff from a range of Section 75 groups.</p>	<p>to the particular needs of those with or caring for somebody with a rare disease.</p>
<p>Theme 8: Board composition</p> <p>It could also be worth examining whether those with extensive caring responsibilities are also under represented.</p>	<p>This will be raised in discussions with the Office for Public Appointments or Public Appointments Unit.</p>
<p>Conclusions</p> <p>We are keen that proactive measures are taken to facilitate the promotion of equality of opportunity between the categories identified in Section 75 (1); and specific Themes and Actions are undertaken to address inequality of opportunity in relation to rare disease. We feel strongly that rare diseases, and the specific issues they raise, should be explicitly referenced in the narrative accompanying the Section 75 Equality Plan 2013 -2018, and all relevant equality plans. In future this would make clear that proposals are fully inclusive of, and applicable to, all patients and carers,</p>	<p>An appendix has now been added to the Action Plan which lists examples of groups covered under the nine equality categories. Specific mention is made therein in respect of rare diseases that fall under the definition of a disability.</p>

and not aimed simply at those affected by common conditions and diseases.

We request that consideration is also given to the modification of existing **staff training**, and that future training is specifically designed, to ensure that participants are alerted to the potential pitfalls of negative attitudes, and related issues that arise simply as a consequence of a condition being rare. For example, doctors or other health professionals not listening to patients and carers, who are “expert” in their condition, and so making inappropriate, even damaging, judgements; or refusing to refer patients to expert centres for a second opinion. We are very keen to contribute constructively to the development of training programmes.

The Agency will raise this recommendation with its HSC partner organisations whose functions relate to education and training of the relevant professions.

Carol McCullough (individual) (Specific comments directed at the Public Health Agency only)	PHA response
<p>concerns about service provision for rare diseases, based on personal experience, with particular reference to:</p> <ul style="list-style-type: none"> • confusion regarding diagnosis during secondary care • action to promote equality for those affected by rare disease should be outlined in all frameworks for delivery of care and equality action plans • measures needed to increase data collection on prevalence of rare disease • need to promote research, education and delivery of appropriate care including timely access to expert care beyond NI 	<p>In our role in supporting the Commissioning process we will bring this information to the attention of the Health and Social Care Board.</p> <p>An appendix has now been added to the Action Plan which lists examples of groups covered under the nine equality categories. Specific mention is made therein in respect of rare diseases that fall under the definition of a disability.</p>

Conclusion

This report reflects the consultation exercise undertaken jointly by the Public Health Agency and its partner organisations to capture feedback on the content of organisations' Equality Action Plans. The Agency's Management Team has considered the submissions from each of the consultees and acknowledge the commitment of all those who responded.

Where it has been possible we have addressed comments raised and reviewed our draft action plan accordingly.

Equality Action Plans for each of the organisations named in Table 1 are now available on their websites. These plans will be reviewed on an ongoing basis and an annual report on progress will be submitted to the Equality Commission for Northern Ireland.



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