Appendix 2 - Equality Impact Assessment - Standard Assessment Template

Section A: Assessment

Name of Policy: All Wales Paediatric Advance Care Plan (PAC-Plan)

Person/persons conducting this assessment with Contact Details:

Dr. Richard Hain, Consultant in Paediatric Palliative Medicine and Chair of the Ethics Committee
Dr Sian Moynihan Consultant Community Paediatrician
Rose Whittle Community Services Manager
Cardiff and Vale UHB Ethics Committee
Parent representative

Date: 24th June 2016

1. The Policy

Is this a new or existing policy? Existing

What is the purpose of the policy?

Around 450 children in Cardiff and the Vale University LHB have a chronic medical condition that is expected to lead to their death within childhood. For most, deterioration towards death is slow, taking place over several years. The acute episode causing death is typically preceded by several similar episodes in which death is possible or even expected, but does not occur. The Paediatric Advanced Care Planning (PAC-Plan) provides a structured approach to discussions about end of life in children that are initiated by clinicians in a timely fashion when there is still time for parents and clinicians to explore a consensus about what is in the child's interests.

How do the aims of the policy fit in with corporate priorities? i.e. Corporate Plan

Who will benefit from the policy? Children with life-limiting conditions and the families caring for them.

What outcomes are wanted from this policy?

1. Increase in proportion of families who are able to care for their child in the place of their preference at the end of life.

2. Decrease in number of irreconcilable disagreements between families and healthcare team about what interventions are appropriate for a child at the end of life.

Are there any factors that might prevent outcomes being achieved? (e.g. Training/practice/culture/human or financial resources)

- Lack of awareness of the policy
- Difficulty locating the completed documents at the time interventions are considered
- Reluctance to engage with the process on the part of professionals and/or families
- Misunderstandings about the nature of the process (especially assuming it authorises or requires certain interventions to be automatically withheld)

2. Data Collection

What qualitative data do you have about the policy relating to equalities groups (e.g. monitoring data on proportions of service users compared to proportions in the population)?
What quantitative data do you have on the different groups16 (e.g. findings from discussion groups, information from comparator authorities)?
Please indicate the source of the data gathered? (e.g. Concerns/Service/Department/Team/Other)
What gaps in data have you identified? (Please put actions to address this in your action plan?)

There is evidence that BME groups are under-represented among those using palliative care services, despite being over-represented among the families caring for children with life-limiting conditions .[1]

Over the whole of the last decade, the prevalence of life-limiting conditions has been consistently highest for children in social deprivation category 5 and lowest in category 1.

These figures show that the burden of caring for a child with an LLC is most likely to fall on BME families and those living in areas of high social deprivation, but that they are also the families least likely to access specialist palliative care services that can facilitate choices at the end of life.

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[1] Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA, et al. Rising national prevalence of life-limiting conditions in children in England. Pediatrics. 2012 Apr;129(4):e923-9. PubMed PMID: 22412035. Epub 2012/03/14. eng.
Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC, Hain icwR. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity. Leeds: University of Leeds/Children's Hospices UK, 2011.

The most important gap in these data is the extent to which the PAC-Plan achieves its aims of giving a voice to families, and therefore improving family choice at the end of life. The PAC-Plan documentation is designed to be audited over time so that this can be monitored.

3. Impact

Please answer the following
Consider the information gathered in section 2 above of this assessment form, comparing monitoring information with census data as appropriate (see www.ons.gov.uk Office National Statistics website) and considering any other earlier research or consultation. You should also look at the guidance in Appendix 1 with regard to the protected characteristics **stating the impact and giving the key reasons for your decision.**

Do you think that the policy impacts on people because of their age? (This includes children and young people up to 18 and older people)

Yes. The policy relates only to those younger than 18 years, although with an appropriate amendment in the policy, the documentation could support older patients, especially those who lack capacity under the MCA (2005).

Do you think that the policy impacts on people because of their caring responsibilities?

Yes. It will enable those caring for children with life-limiting conditions to explore and articulate preferences for how their child should be managed at the end of life. When options become limited because of a child's deteriorating condition, it will provide an opportunity for sensitive and timely exploration of the reasons.

Do you think that the policy impacts on people because of their disability? (This includes Visual impairment, hearing impairment, physically disabled, Learning disability, some mental health issues, HIV positive, multiple sclerosis, cancer, diabetes and epilepsy.)

The policy is aimed at improving dying in children with life-limiting conditions, around two thirds of whom are significantly cognitively and/or physically impaired. Many will have visual and hearing impairment and 70% will have learning disability as well as physical disability[2]

Do you think that the policy impacts on people because of Gender reassignment? (This includes Trans transgender and transvestites)

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[2] Wood F, Simpson S, Barnes E, Hain R. Disease trajectories and ACT/RCPCH categories in paediatric palliative care. Palliat Med. 2010;24(8):11. PubMed PMID: 20719816. Epub 2010/08/20. Eng.

The number of chilren and young people treated for gender dysphoria is rising [3] and this will be reflected in the population of children with life-limiting conditions as in the population at large. The sexuality of most patients affected by the Plan will not be known with certainty because of cognitive impairment, and lack of congruence between body sex and gender identity will not be knowable in most. That is least likely to be true in the group with Duchenne Muscular Dystrophy and those with cancer. The Plan focuses, however, on the needs of the individual child and makes minimal assumptions about sexuality.

Do you think that the policy impacts on people because of their being married or in a civil partnership?

The Plan makes minimal assumptions about marital status. Its only relevance is indirect (because it impacts on who has parental responsibility over the child). The Plan refers to parental responsibility, because that is relevant to the authority of the person completing the form. Marital status and parental responsibility are linked in that if an unmarried father is not present and does not sign the register of births, his details will not be included on the birth certificate and he will not automatically have parental responsibility for his child.[4] It's important to point out that the Plan is not a legal document, and the lack of parental responsibility does not preclude someone from expressing a view, though it would preclude them from giving consent for the information to be disseminated.

With that in mind, it's extremely unlikely that the Pac-Plan will impact differently on people in marriages or civil partnerships and those who are not.

Do you think that the policy impacts on people because of their being pregnant or just having had a baby?

Instances in which end of life care needs to be provided alongside antenatal care during pregnancy are rare but well-recognised.[5] The Pac-Plan relates to end of life care in the child, and will not impact on the care of a dying mother. The Plan might, however, impact on the care of babies who have not yet been born but are not expected to survive (such as those with anencephaly or some severe chromosomal abnormalities). The discussions represented by the Pac-Plan might result in a mother deciding to proceed with a pregnancy she would otherwise have chosen to terminate, since the Plan allows her to be confident that the dying baby will receive good palliative care and be comfortable during his or her short life.[6]

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[3] http://www.telegraph.co.uk/news/health/news/11519603/Rise-in-child-transgender-referrals.html (accessed July 2016)

[4] http://www.oneplusone.org.uk/content_topic/married-or-not/children/ (accessed July 2016)

[5] Best Pract Res Clin Obstet Gynaecol. 2001 Apr;15(2):323-31

[6] Hain R. Teddy Houlston's short life tells us so much about what it is to be human. Observer. 2015 26th April 2015

Do you think that the policy impacts on people because of their race? (This includes colour, nationality and citizenship or ethnic or national origin such as Gypsy and Traveller Communities.)

Despite being over-represented among the families caring for children with life-limiting conditions, there is evidence that BME groups are under-represented among those using palliative care services.[7] It is known that the palliative care needs of Romany families in the UK are not always well met. [8]

These studies are mainly of adults and do not relate directly to children, but it is reasonable to extrapolate their findings. The main impact of the Pac-Plan would be to help reduce that unequal access to services by encouraging clinicians to recognize the need to offer end of life care in a timely and sensitive fashion.
The Plan is, however, currently available only in English, so that although it will still support the care of families whose first language is not English, it will be less effective in those families.

Do you think that the policy impacts on people because of their religion, belief or non-belief? (Religious groups cover a wide range of groupings the most of which are Buddhist, Christians, Hindus, Jews, Muslims, and Sikhs. Consider these categories individually and collectively when considering impacts)

Certainly to the extent that those impact on language (see above).

There is evidence that poor access to palliative care services is related to cultural concerns about the ideology represented by palliative care itself (ie the belief that it can be acceptable to allow death to occur without intervening to try to stop it) and about its ethos, which is often seen to be rooted in a Christian worldview[9] Religious belief is also often thought by clinicians to be the cause for difficulties in reaching consensus with families regarding care at the end of life[10]. To the extent that that is true, this policy will also offer particular benefits.

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[7] Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA, et al. Rising national prevalence of life-limiting conditions in chin in England. Pediatrics. 2012 Apr;129(4):e923-9. PubMed PMID: 22412035. Epub 2012/03/14. eng.
, Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC, Hain icwR. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity. Leeds: University of Leeds/Children's Hospices UK, 2011.

[8] Jesper E, Griffiths F, Smith L. A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness. Primary Health Care Research & Development. 2008;9(02):157-65.

[9] Gatrad AR, Brown E, Notta H, Sheikh A. Palliative care needs of minorities. BMJ. 2003 Jul 26;327(7408):176-7. PubMed PMID: 12881234. Pubmed Central PMCID: 1126563. Epub 2003/07/26. eng. And Gatrad AR, Sheikh A. Palliative care for Muslims and isses before death. International Journal of palliative nursing. 2002;8(11):526-31.

[10] Brierley J, Linthicum J, Petros A. Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children? J Med Ethics. 2012 Mar 30. PubMed

Do you think that the policy impacts on men and woman in different ways?

Life-limiting conditions are particularly likely among boys.[11]

There is evidence that single-parent families are more likely among those caring for children with LLC,[12] and since a majority of single parents are mothers, any benefits of the PAC-Plan policy will be particularly great among women.

Do you think that the policy impacts on people because of their sexual orientation? (This includes Gay men, heterosexuals, lesbians and bi-sexuals)

There is evidence that adult members of the LGBT community feel excluded from good quality care at the end of life. [13] Many concerns centred around reluctance of LGBT to engage with services for fear of heteronormative assumptions about relationships (especially in relation to defining who is next of kin) and language. The PAC-Plan makes no such assumptions, referring throughout only to mother, father or parent. It is unlikely that members of the LGBT community would feel reluctant to engage with the process on those grounds, and it is plausible that one result of having the Plan available will be to encourage clinicians to be more proactive in involving parents generally, whatever their sexual orientation, improving access to specialist palliative care services.

Do you think that the policy impacts on people because of their Welsh language?

Yes. It is currently available only in English, so that although it will still support the care of families whose first language is Welsh, it will be less effective in those families.

4. Summary.

Which equality groups have positive or negative impacts been identified for (i.e. differential impact).
Is the policy directly or indirectly discriminatory under the equalities legislation?
If the policy is indirectly discriminatory can it be justified under the relevant legislation?

There is no group on whom the impact of this policy is likely to be negative.

PMID: 22465877. Epub 2012/04/03. Eng.

[11] Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC, Hain icwR. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity. Leeds: University of Leeds/Children's Hospices UK, 2011.

[12] Totsika V, Noyes J, Hastings R, Hain R. Report on DicData group of Projects (supplementary/final report). Bristol, UK: Together for Short Lives, 2013.

[13] http://www.ncpc.org.uk/lgbt (accessed July 2016)

The policy is likely to have the greatest positive impact among women, black and minority ethnic groups, families whose religious views are felt by professionals to be the cause of unreasonable care decisions at the end of life, and families from areas of high social deprivation.

Because it focuses on the nature and needs of the individual child, and the individual members of the child's family, the sexual orientation of the child or parent (even if known and made explicit) is unlikely to be relevant to the impact of the Plan for most. The same is probably true for children of transgender parents or who are themselves transgender, but the data are not there and it is an issue that may become more important in the future as the incidence of gender incongruence in young people is rising.

Its positive impact is likely to be less among those whose first language is not English, including those whose first language is Welsh.

Appendix 3

Cardiff and Vale University Health Board
Action Plan

Section B: Action

5. Please complete your action plan below. Issues you are likely to need to address include

•What **consultation** needs to take place with equality groups (bearing in mind any relevant consultation already done and any planned corporate consultation activities?)

Alun Williams, Welsh Language Officer, CVUHB
Reg Cotter and Helen Bennett, Co-chairs, Rainbow LGBT FFlag Network, CVUHB

• What **monitoring**/evaluation will be required to further assess the impact of any changes on equality target groups?

The Pac-Plan will be an important tool for auditing the effectiveness of the paediatric palliative care service., including the extent to which minority groups feel able to access the service.

Equalities Impact Assessment Implementation Action Plan

Issue to be addressed	**Responsible Officer**	**Action Required**	**Timescale for completion**	**Action Taken**	**Comments**
Review by team who conducted original assessment	Richard Hain	Circulate to team	June 2016		No new comments made
Opinion from Ethics Committee	Richard Hain	Submit to CVUHB CEC	August 2016	Reviewed on 14th July 2016	Ethics committee question whether this should actually be guidance rather than policy.
Review by Julia Harper for	Richard Hain	Email to JH	June 2016	Reviewed July 2016	Amendments made

comments on corporate context					
Review by Keithley Wilkinson	Richard Hain	Email to KW	June 2016	Reviewd July 2016	Amendments made
Reg Cotter and Helen Bennett, Co-chairs, Rainbow LGBT FFlag Network, CVUHB	Keithley Wilkinson	Email to RC, HB	July 2016	No response received (Oct16)	
Review by Wahida Kent (PhD student examining BME in LLC)	Richard Hain	Email to WK	June 2016	WK not present at CEC meeting when discussed.	
Audit of equality impact after launch	Palliative Care SpR	Audit cycle	August 2017, 2018		
Alun Williams, Welsh Language Officer	Richard Hain	Email to AW	July 2016	Response Aug 16	Agrees Welsh Language version needed

6. Report, publication and Review
Please record details of the report or file note which records the outcome of the EQIA together with any
actions / recommendations being pursued (date, type of report etc)

Quality Safety and Experience Committee

Please record details of where and when EQIA results will be published
Once the policy has been approved the documentation will be placed on the intranet and internet.

Audit results will be presented at the usual departmental and wider LHB audit meetings.

Please record when the EQIA will be subject to review.

Name of person completing Dr Richard Hain, Consultant in Paediatric Palliative Medicine
Signed ____
Date: ____

Name of Senior Manager Authorising Assessment and Action Plan for publication Dr Graham Shortland, Medical Director
Signed: ____
Date: ____

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Appendix 4
Format for publication of EQIA results
Executive Summary
This is an all-Wales policy. Responsibility for implementing it falls to all employees and Board members, volunteers, agents or contractors delivering services or undertaking work on behalf of the Cardiff and Vale University LHB.

Evidence suggests the policy is likely to have an overwhelming positive impact in accordance with equality, Welsh language and human rights legislation and with the aims of this policy, which adheres to and illustrates that legislation.

Background
Cardiff and Vale UHB is committed providing services to the public in a way that reflects their individual needs and does not discriminate, harass or victimise individuals or groups. The Pac-Plan is built around those principles.

Involvement in the review included staff representatives as well as the Cardiff and Vale University Health Boards' Rainbow LGBT FFlag Network (by email) and through the Welsh Language Officer (by email). It was also put out for consultation on the UHB intranet.

- The aim is to facilitate timely, sensitive and appropriate introduction of discussions about end of life care for children whose conditions cannot be cured.
- This is an all Wales policy that has been endorsed by the Medical Directors' group. It was approved by the Cardiff and Vale UHB in 2013.
- This review was carried out by Dr. Richard Hain, Consultant in Paediatric Palliative Medicine and Chair of the Ethics Committee, Dr Sian Moynihan Consultant Community Paediatrician, Rose Whittle, Community Services Manager, Cardiff and Vale UHB Ethics Committee

The scope of the EQIA
The likely effects were evaluated on the basis of existing research, other related EQIA policies and through consultation with relevant stakeholders.

Key findings
The effect of this policy will be overwhelmingly positive in the care of all children at the end of life. There is strong evidence that this policy will demonstrate UHB's commitment to the equality, diversity and human rights agenda because of its focus on the individual needs of the child and the parent.

During the consultation, the wording of the policy was amended in line with comments of reviewers.

Recommendations

The main change to the policy was the update the name of the document to the Paediatric Advance Care Plan, in accordance with advice from reviewers. It is recommended that this policy be adopted by CVUHB.

It is recommended that this policy is reviewed in line with the current guidelines of the UHB, unless there is a change in relevant legislation in which case, the policy should be reviewed within 6 months of any new legislation and changes made accordingly. The policy will be monitored and reviewed by all-Wales Paediatric Palliative Care Network

It will be issued via the intranet, email to consultants in paediatrics and palliative medicine, and to Clinical Boards/Corporate areas management teams.