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Aneurin Bevan University Health Board

Disclosure of Diagnosis and Early Counselling following the Birth of a Baby with Congenital Malformation (s) Guideline

N.B. Staff should be discouraged from printing this document. This is to avoid the risk of out of date printed versions of the document. The Intranet should be referred to for the current version of the document.

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Introduction

Parents who have been anticipating the birth of a normal baby are generally shocked having to come to terms with a malformation(s). They have to grieve for the loss of the normal baby they were expecting, thus a period of grieving often follows disclosure (Silverton, 1993).

However, with advancing technology a number of malformations are detected during the antenatal period and some preparation of women and their families may have already occurred. The professionals providing care for women should communicate care that has been provided to date, in addition to ensuring a written management of care plan in the woman's notes for labour, delivery and planned after care.

The following is a guideline for breaking news to parents following the birth of a baby with major congenital malformation or who is likely to be severely disabled as a result of such malformation.

There is **no** single 'correct' approach. The requirement is for flexibility, sensitivity to individual needs and ability to empathise and communicate with parents honestly and directly.

Policy Statement

Following the birth of a baby with a congenital malformation, Staff employed by Aneurin Bevan Health Board will be sensitive to the needs of the parents and the wider family and will seek to communicate the news of the malformation(s) honestly and directly.

Aims

The purpose of this document is to provide advice and guidance for clinicians when giving a diagnosis of congenital malformation (s) following the birth of a baby.

Guideline in Disclosure of diagnosis and early Counselling

1. Disclosure of diagnosis must be done by a senior paediatrician (consultant neonatologist/senior specialist registrars who have undergone training in counselling procedures).
2. Parents should be told together. (If the father is not available arrangements should be made to see him at the earliest opportunity). In cases of a single parent, make enquiries if

mum would like the support of a close friend/partner or close relatives. (Raphael-Leff, 1993).

3. Disclosure must be in a private place without any interruptions (bleep, telephone, etc). Where there is a suspicion that the baby may have a congenital malformation, consideration is given as to where the mother is placed in the post natal ward.
4. Allow plenty of time, do not rush; patience and an unhurried approach are qualities that establish trust between family members and staff (Vulliamy, 1984).
5. Use the baby's name throughout and wherever possible keep the child with the parents when sharing the findings and diagnosis, promoting bonding and mother/fetal attachment (Raphael-Leff, 1993).
6. Convey warmth, understanding and respect for the mother and child.
7. Be honest and truthful in sharing information, acknowledging the limitations of professional knowledge.
8. Use plain understandable language, giving explanations that will build up parents' confidence to handle the situation. Offer to introduce to another parent.
9. Offer leaflets on the child's condition and the range of services available in the locality.
10. Offer to help break news to family and friends.
11. Offer a second interview within seven days or as necessary and invite parents to keep a note of any questions to ask at the next session.
12. Parents need privacy with each other after the initial interview.
13. Ensure effective communication with the child's GP and provide the notes of the disclosure meeting and all other necessary information, following parental consent and in line

with the Aneurin Bevan Health Board Good Practice in consent Policy 2009 (ABHB/Clinical/0004)

14. Written information to parents following the meeting to clarify what was said for future reference in the language appropriate to parents. Give a telephone number so that parents can ask further questions as necessary.

Practical Help and Information

- Parents' information needs vary. They should be told of the support available from social services and education authorities – as needed.
- Give pamphlets both about the child's condition and about practical help. Inform them about benefits and services in the locality.
- Discuss several long-term support arrangements, i.e. counselling of siblings and other close family members (grandparents).
- Offer contact with another parent or parent group only when they indicate they would like such contact.
- Collaboration between professionals and voluntary organisations should ensure that parents benefit fully from the help available in the community.

On going counselling support to child and family is essential at different stages of life and not just at disclosure of diagnosis.

Process

1. Midwife/ paediatrician - deal with immediate needs of the baby as appropriate
2. Examine the baby, highlight the positive findings before expressing concerns. Avoid using derogatory and beware of terms such as '*funny looking*', and beware of the danger of giving unconscious messages through body language before concerns have been shared with parents.

3. Ensure parents see and hold the baby. Early mother/parent-infant contact promotes bonding and affection between parents and baby (Enkin et al, 2000).
4. Inform consultant neonatologist as soon as possible to facilitate the process of the baby being checked and confirming congenital malformation(s). The consultant neonatologist will be responsible for initially disclosing the diagnosis and providing counselling support.

Inform community midwives, health visitors and the general practitioner of congenital malformation(s)

Providing brief written information on condition and care plan (discussed with parents) and follow-up arrangements.

A decision should be made to refer the child to borough based consultant paediatrician (preferably via the CDT – depending on the needs of the child) for future follow up, after full parental agreement.

In a few selected cases with very complex needs, a small planning meeting is desirable preferably before mum and the baby leave hospital or soon after discharge. The purpose of this meeting is to ensure a smooth transition between hospital and community support services. Parents should be in control at all times about services and agencies they wish to be involved with.

The core team at the meeting includes representatives from each service as appropriate.

Core Team:

- i. Parents
- ii. Lead consultant neonatologist
- iii. Consultant paediatrician
- iv. Health visitor/ general practitioner
- v. Neonatal nurse
- vi. Midwife
- vii. Specialist social worker

5. Brief minutes of the meeting and Care Plan should be offered to parents with copies to team members following parental consent.
6. Offer another appointment within two weeks to address new concerns of queries parents may wish to discuss.
7. CARIS (Congenital Anomaly Register and Information Services) form to be completed by the neonatal team.

8. Appropriate referral to the clinical geneticist should be considered as needed following full parental consent.
9. Ensure records are maintained (NMC 2009) and the midwife at delivery must ensure CSC birth record indicates malformation.
10. Midwives may choose to access the clinical supervisor for midwives where indicated.

Training

Training will be identified as part of the junior medical staff training plan.

References

Enkin,M; Kierse,M.J.N.C.; Neilson,J; Crowther,C; Duley,L; Hodnett,E. and Hofmeyr,J. (2000) (3rd edition) *A guide to effective care in pregnancy and childbirth*, Oxford University Press

Raphael-Leff,J (1993) *Psychological Processes of Childbearing*, Chapman & Hall, London

Silverton,L (1993) *The Art and Science of Midwifery*, Prentice Hall, New York

Nursing & Midwifery Council (2008) *Standards of conduct, performance and ethics for nurses and midwives*, NMC, London

Nursing & Midwifery Council (2009) *Record Keeping: Guidelines for Nurses and Midwives*, NMC, London

Vulliamy,D.G (1984) (5th edition) *The Newborn Child*, Churchill Livingstone, Edinburgh

SCOVO Parents Deserve Better (1991)

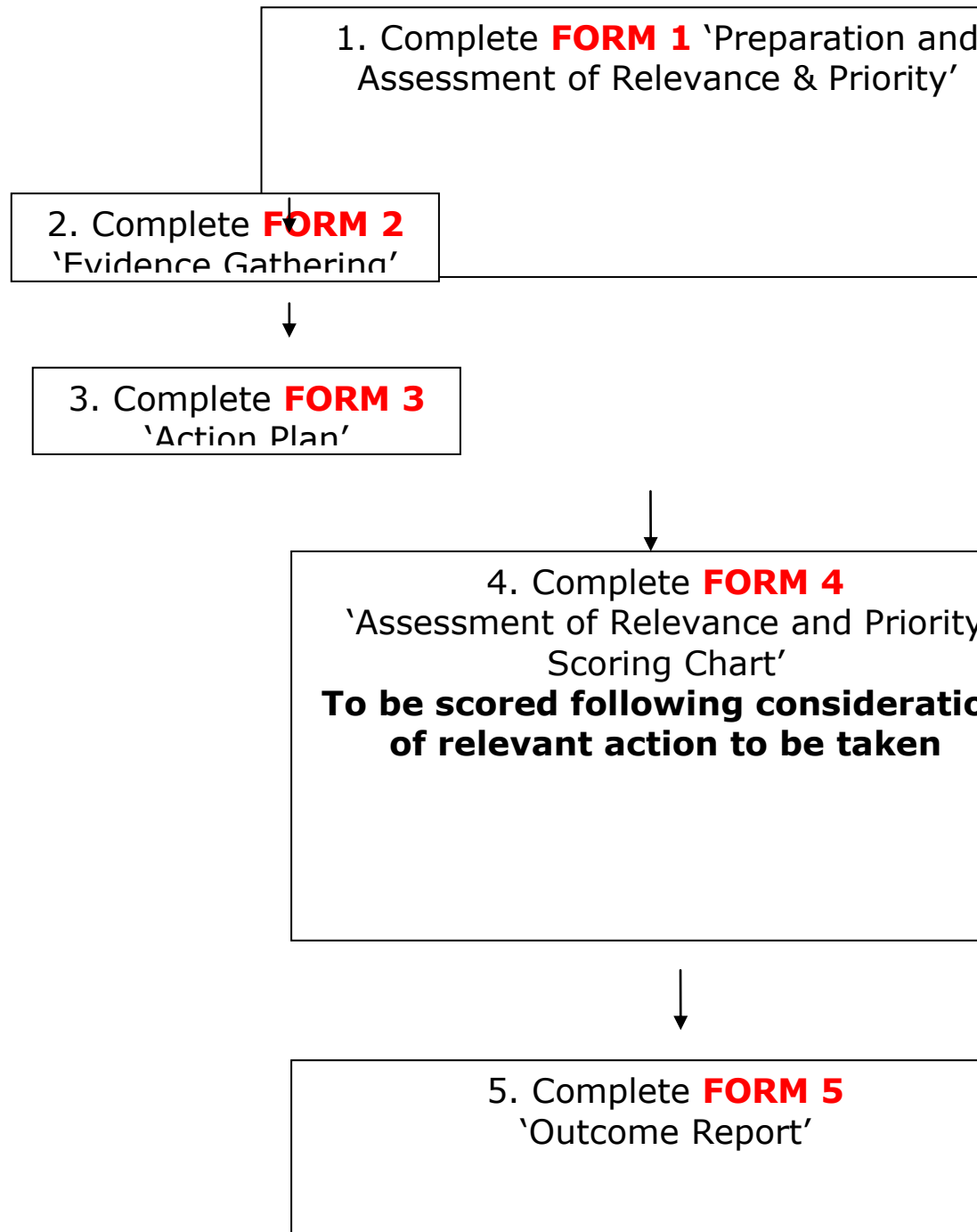
SCOPE Right from the Start (1996)

APPENDIX 4

EQUALITY IMPACT ASSESSMENT GUIDANCE

Aneurin Bevan Health Board

Flowchart for the Completion of the EqIA Paperwork



FORM 1



Equality Impact Assessment (EqIA)

Form 1

Part A: Preparation and Assessment of Relevance and Priority

Step1: Preparation

1 What are you equality impact assessing?

Disclosure of diagnosis and Early Counselling following the Birth of a Baby with Congenital Malformation(s) guideline

2. Policy Aims and Brief Description - What are its aims, give brief description.

The purpose of this document is to provide advice and guidance for clinicians when giving a diagnosis of congenital malformation (s) following the birth of a baby.

3. Who Owns the Policy? - Who is responsible for the policy/work?

Author – Mrs S Papworth Consultant Neonatologist
Owner – Maternity Clinical Effectiveness Forum

4. Who is involved in undertaking this EqIA? - Who are the key contributors to the EqIA and what are their roles in the process?

Mrs S Papworth Consultant Neonatologist
Mrs D Pimbley Quality & Safety Lead F&T

5. Other Policies- Describe where this policy/work fits in a wider context.

Labour ward guidelines

6. Stakeholders – Who is involved with or affected by this policy?

Maternity staff within ABHB
Pregnant Women cared for within ABHB

7. What factors may contribute to the outcomes of the policy? What factors may detract from the outcomes? These could be internal or external factors.

Accessibility and distribution of guideline

Next Steps

For the next stage of the EqIA process please see form:
Part A, Step 2 - Evidence Gathering.

FORM

Aneurin Bevan Health Board Equality Impact Assessment: Part A, Step 2 Evidence Gathering

Equality Strand	Evidence Gathered	Does the evidence apply to the following with regard to this policy/work? Tick as appropriate									
Race	There is no evidence that a persons race will affect the presence of a congenital abnormality or the disclosure of diagnosis	Eliminating Discrimination and Eliminating Harassment	✓	Promoting Equality of Opportunity	✓	Promoting Good Relations and Positive Attitudes	✓	Encouraging Participation in Public Life	Taking account of difference even if it involves treating some individuals more favourably		
Disability	There is no evidence identified to demonstrate that a persons disability will affect the presence of a congenital abnormality or the disclosure of diagnosis		✓		✓		✓				
Gender	There is no evidence identified to demonstrate that a persons gender will affect the presence of a congenital abnormality or the disclosure of diagnosis as this guideline is specifically for pregnant women		✓		✓		✓				
Sexual Orientation	There is no evidence identified to demonstrate that a persons sexual orientation will affect the presence of a congenital abnormality or the disclosure of diagnosis		✓		✓		✓				
Age	There is no evidence identified to demonstrate that a persons age will affect the presence of a congenital abnormality or the disclosure of diagnosis		✓		✓		✓				
Religion/ Belief	There is no evidence identified to demonstrate that a persons religion/belief will affect the presence of a congenital abnormality or the disclosure of diagnosis		✓		✓		✓				
Welsh Language	There are facilities for translation if required		✓		✓		✓				

Human Rights	
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*This column relates only to disability due to the DDA 2005 specific duty

FORM

Aneurin Bevan Health Board Equality Impact Assessment Action Plan

Name of Policy:

Recommendation	Expected Outcome	Divisional/Department Response	Responsible person	Progress to date
No additional actions required				

FORM

Aneurin Bevan Health Board: Equality Impact Assessment Assessment of Relevance and Priority – Scoring Chart

Name of Policy:

Equality Strand	Evidence: Existing evidence to suggest some groups affected gathered from Part A Step 2.	Potential Impact: Nature, profile, scale, cost, numbers affected, significance.	Decision: Multiply 'Evidence' score by 'Potential Impact' score. <i>* please see bottom of the page for maths rule</i>
Race	1	3	3
Disability	1	3	3
Gender	1	3	3
Sexual Orientation	1	3	3
Age	1	3	3
Religion/ Belief	1	3	3
Welsh Language	1	3	3
Human Rights	1	3	3

Evidence Available		Potential Impact		Impact Decision	
3	Existing data/research	-3	High negative	-6 to -9	High Impact (H)
2	Anecdotal/awareness data only	-2	Medium negative	-3 to -5	Medium Impact (M)
1	No evidence or suggestion	-1	Low negative	-1 to -2	Low Impact (L)
		0	No impact	0	No Impact (N)
		+1	Low positive	1 to 9	Positive Impact (P)
		+2	Medium positive		
		+3	High positive		

* Rule: Multiplication of a negative number by a positive number yields a negative result.
 Multiplication of two positive numbers yields a positive result.
 Multiplication of two negative numbers yields a positive result.

FORM 5

Aneurin Bevan Health Board



Equality Impact Assessment (EqIA) Outcome Report

Policy Title:	Disclosure of diagnosis and Early Counselling following the Birth of a Baby with Congenital Malformation(s) guideline
Organisation:	Aneurin Bevan Health Board
Name of policy Assessors:	Mrs S Papworth Consultant Neonatologist Mrs D Pimbley Quality & Safety Lead F&T
Division/ Department:	ABHB Neonatal Services ABHB Maternity services
Proceed to Full EqIA:	The assessors are satisfied that as there are no negative impacts identified in this assessment a full EqIA is not required.
Summary of the EqIA process and key points to be actioned:	This EqIA has been undertaken using the tool kit designed by the NHS Wales Centre for Equality & Human Rights. The tool kit gives due consideration to each statutory limb of the Equality Act (2010) and in keeping with an inclusive equality agenda also includes consideration of the Welsh Language Act and the Human Rights Act. This report is not intended to provide a definitive account of the content and outcome of the EqIA screening process but offers a summary of the findings. In this instance no negative differential is identified
Responsibility for validation of the EqIA:	Maternity Services Clinical effectiveness Forum
Date:	28 March 2013
Monitoring Arrangements:	This Guideline will be monitored via the Maternity Services Clinical Effectiveness forum
Policy expiry date:	28 March 2016

This information is available on request in a range of accessible formats, Welsh and other community languages as required.

**For more information please contact:
Aneurin Bevan Health Board Policy Process
Manager on 01495 765460**

APPENDIX 5

CHECKLIST FOR THE APPROVAL AND RATIFICATION PROCESS OF POLICIES AND OTHER WRITTEN CONTROL DOCUMENTS

**CHECKLIST FOR THE APPROVAL AND RATIFICATION OF POLICIES
AND OTHER WRITTEN CONTROL DOCUMENTS**

Please note that no policies or other written control documents should be taken to the [enter sub committee name] for ratification unless they have been seen and approved by the [enter the name of the sub group or forum].

Name of Policy or written control document:

..... Disclosure of diagnosis and Early Counselling following the Birth of a Baby with Congenital Malformation(s) guideline

Owner(s): ...Maternity clinical effectiveness forum

Review Date:April 2016.....

1. Please specify the date and name of person who carried out the policy or other written control document Equality Impact Assessment

Date:13/3/2013..... Name : S Papworth &

2. Have you taken into consideration the relevant legislation that may be applicable to this policy or other written control document?

Y N

Comments :

3. Has a patient information leaflet been developed to assist this policy or written control document?

Y N

Not Applicable

If yes, is the information available in the variety of accessible formats and languages? *(including welsh and other community languages as appropriate)*

Comments :leaflets available for a verity of congenital malformations.

4. Where appropriate, have you consulted with the relevant services/personnel throughout the Aneurin Bevan Health Board when completing the policy or other written control document? Y N

(e.g. Voluntary, Legal, Pharmacy, IT, Finance, personnel, etc.)

Comments :

5. If applicable, please state what training has been identified as a result of this policy or other written control document, and what has been taken:
(Has the training department been informed of any training needs?)

6. ...Training is identified as a part for junior medical staff training plan
Have the necessary users been consulted in the development of this policy or written control document?

(e.g. Aneurin Bevan Health Board, Division/Locality wide, Third Sector, etc.)

Y N Not

Please provide details: ...All Senior obstetricians, senior midwifery staff, community paediatricians and neonatologists have been consulted

7. Has the necessary Equality Impact Assessment documentation been completed?

Y N

8. Has the necessary Environment Impact Assessment been completed?

Y N Not

If no, give reason(s):

Ratification

The [enter name of committee, group or forum] has considered the information and agrees/ratifies on [insert date].

Chair signatureMrs J Singh.....