Alberta Health Services

Newborn Metabolic Screening Program

A Blue Print for Development to Dissemination: A Community Health Nursing Change Management Approach

7th National Community Health Nursing Conference, Kelowna, BC

June 19, 2013

Maryann Kusmirski, RN MN

Alison Nelson, RN MN

Teresa Earl, BCS

Objectives

- To increase participants' awareness and knowledge of an innovative change management approach to developing and distributing community health nursing resources.
- To increase participants' understanding of the applicability of an innovative change management approach within their community health nursing practice

Outline

- Alberta context
- Development to distribution steps
- Exemplar: Staff education resources
- Adapting the approach

Alberta context

Alberta Health Services

- North Zone
- Edmonton Zone
- Central Zone
- Calgary Zone
- South Zone

90,000 employees

3.8 million Albertans

51,000 births/year

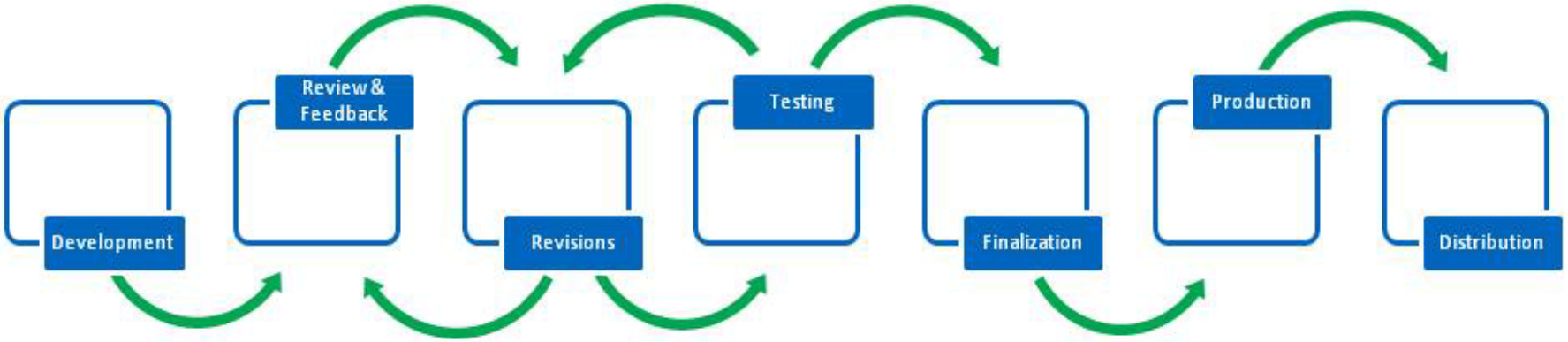
Development to distribution steps

- Guide standardization and utilization of resources
- Integrate community health nursing, project management, health promotion, change management
- Are adaptable and transform concepts from development to distribution, can be used for ongoing review/updates
- Include stages and steps to ensure multiple levels of approval

Alberta Health Services

Newborn Metabolic Screening Program

Implementation Steps: *From Development to Distribution*



Communication
Knowledge Exchange
Evaluation

Exemplar: Staff education resources

Alberta Health Services
Newborn Metabolic Screening Program

Why does my baby need to be screened?

Does my baby really need newborn blood spot screening?

- Newborn blood spot screening is the best way to tell if your baby has a treatable condition that you, your doctor or midwife might not know about.
- Your baby may look and act healthy, but could still have a treatable condition.
- Your baby may have a treatable condition even if there is no family history.

What is newborn blood spot screening?

- Newborn blood spot screening has 3 steps:
  - collecting a few blood drops from a heel poke
  - testing the blood spots for 17 treatable conditions
  - helping your baby get other testing and treatment if needed

What conditions does newborn blood spot screening look for?

- Newborn blood spot screening looks for 17 treatable conditions that include:
  - problems with how the body uses food to grow and develop (metabolic conditions)
  - problems with how the body makes hormones (endocrine conditions)
  - cystic fibrosis, a condition that affects the lungs and digestive system

When is the newborn blood spot screen done?

- The best time for the newborn blood spot screen to be done is when your baby is between 24 and 72 hours old.
- The conditions have to be found as early as possible so that your baby can be treated right away to prevent health problems.

Where is the newborn blood spot screen done?

- Ideally, the newborn blood spot screen is done at the hospital before your baby goes home.
- If the screen is not done at the hospital it will be done at a home visit, at a clinic visit or at a lab in your community.

How is the newborn blood spot screen done?

- The newborn blood spot screen is quick and safe:
  - Your baby's heel is poked using a small plastic object called a lancet.
  - A few drops of your baby's blood are collected onto a blood spot card.
  - Sometimes, another poke is needed to get the right amount of blood.
  - Afterward, cotton gauze may be put on your baby's heel to stop the bleeding.

How can I help my baby during the heel poke?

- You can help your baby by keeping him or her warm, comforted and held closely against your skin.
- Breastfeeding your baby during and after the heel poke often helps.

What are metabolic conditions and how are they treated?

- In metabolic conditions the body can't break down some substances in food like fats, proteins or sugars which your baby needs for healthy growth and development.
- The substances build up in the body and may cause serious health problems.
- Special diets or nutritional supplements are often used as treatment.

Alberta's Newborn Metabolic Screening Program

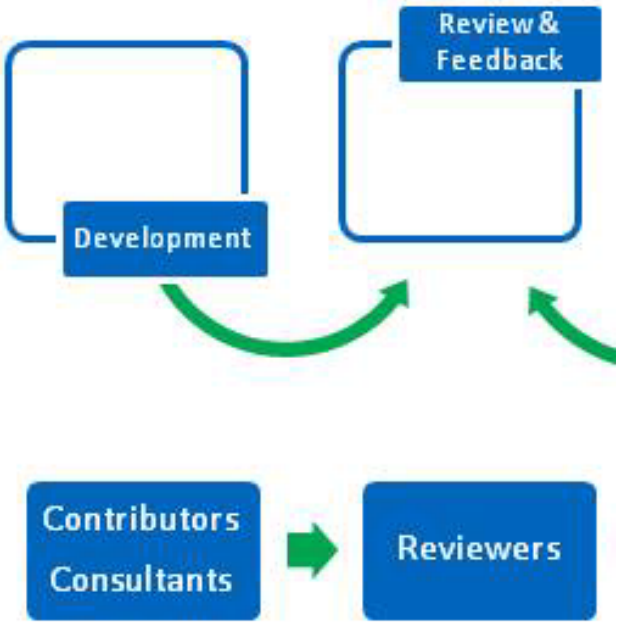
Newborn blood spot screening helps your doctor or midwife find conditions that can be treated early to prevent health problems, improve your baby's health and maybe even save your baby's life.

What is the Newborn Metabolic Screening Program?

- Alberta's Newborn Metabolic Screening (NMS) Program is about health care providers working together with parents or guardians to screen for 17 treatable conditions.
- Early screening helps find conditions that can be treated early, when the treatment can help your baby the most.
- The NMS Program makes sure all screened babies who may have one of the treatable conditions get other testing and early treatment.

Alberta's Newborn Metabolic Screening Program www.albertahealthservices.ca/newbornscreening.asp
APRIL 2013 NMS Program parentwhy V3

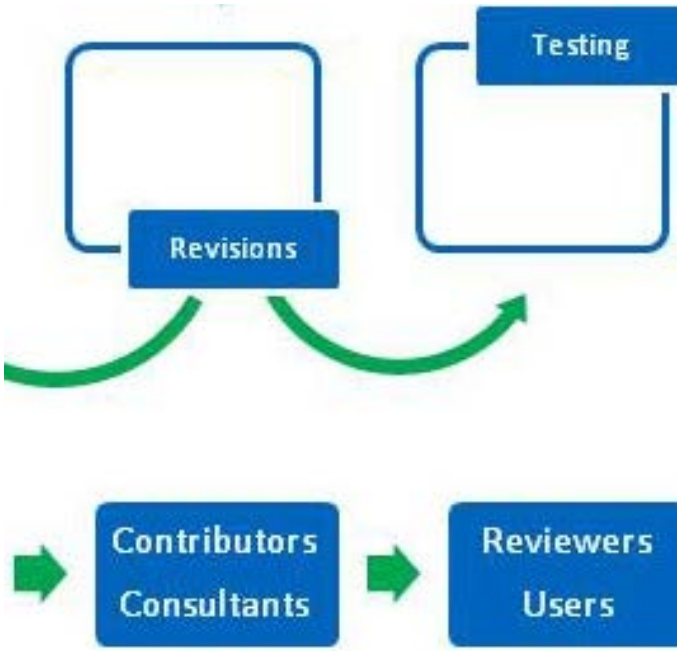
Development and Review/Feedback



- Define messages, target audience, users
- Brainstorm ideas
- Focus on purpose
- Review previous content and comparators
- Write content into bulleted messages (don't develop in final layout e.g., brochure)

Messages and Comparators

Revisions and Testing

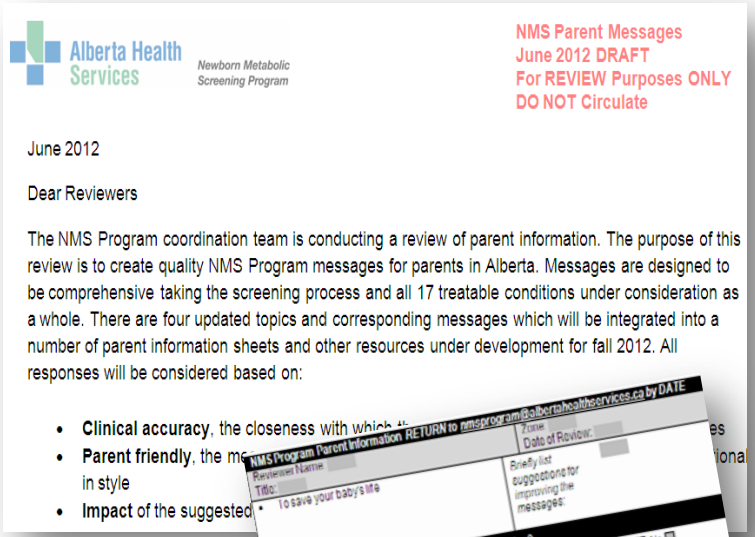


- Determine revision criteria
- Who: Expertise and authority
- What: Content not writing style
- Why: Rationale and evidence
- When: Timelines, extensions
- How: Organize and theme
- Revise content in bulleted messages (don't revise in final layout e.g., brochure)

Alberta Health Services

Newborn Metabolic Screening Program

Electronic Tools



Alberta Health Services Newborn Metabolic Screening Program

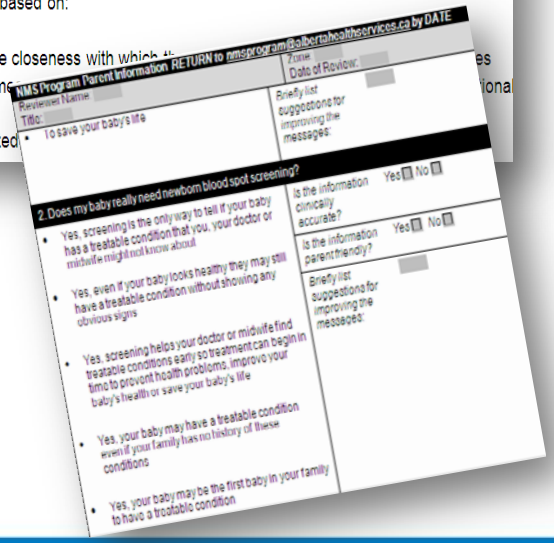
NMS Parent Messages
June 2012 DRAFT
For REVIEW Purposes ONLY
DO NOT Circulate

June 2012

Dear Reviewers

The NMS Program coordination team is conducting a review of parent information. The purpose of this review is to create quality NMS Program messages for parents in Alberta. Messages are designed to be comprehensive taking the screening process and all 17 treatable conditions under consideration as a whole. There are four updated topics and corresponding messages which will be integrated into a number of parent information sheets and other resources under development for fall 2012. All responses will be considered based on:

- **Clinical accuracy**, the closeness with which it
- **Parent friendly**, the me
- in style
- **Impact** of the suggested



NMS Program Parent Information RETURN to nmsprogram@albertahealthservices.ca by DATE

Reviewer Name
Title:
Zone
Date of Review

• To save your baby's life

Briefly list suggestions for improving the messages:

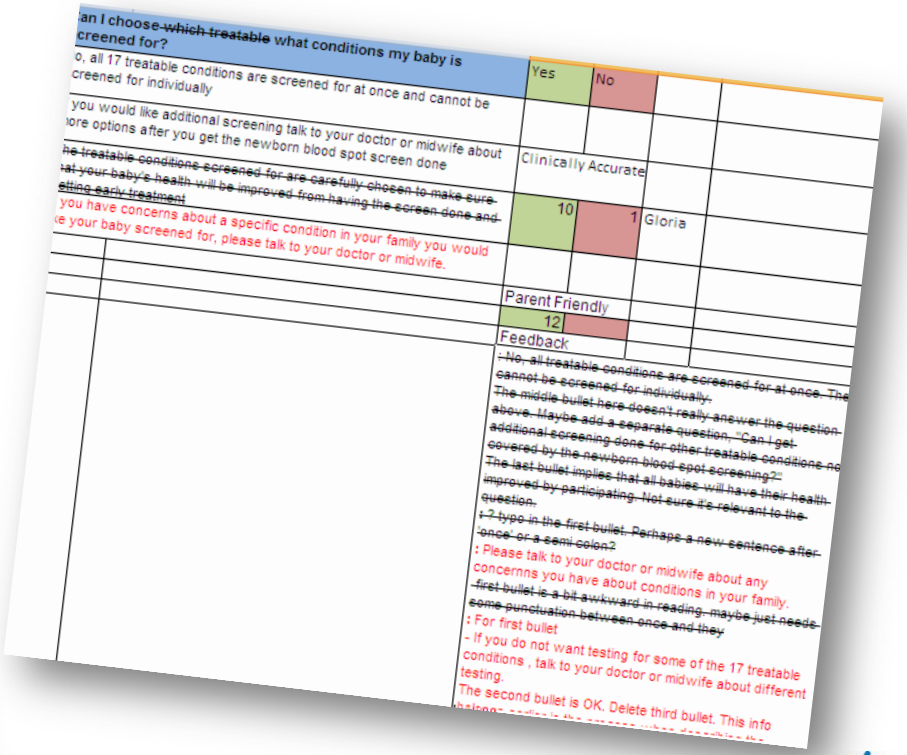
2. Does my baby really need newborn blood spot screening?

- Yes, screening is the only way to tell if your baby has a treatable condition that you, your doctor or midwife might not know about
- Yes, even if your baby looks healthy they may still have a treatable condition without showing any obvious signs
- Yes, screening helps your doctor or midwife find treatable conditions early so treatment can begin in time to prevent health problems, improve your baby's health or save your baby's life
- Yes, your baby may have a treatable condition even if your family has no history of these conditions
- Yes, your baby may be the first baby in your family to have a treatable condition

Is the information clinically accurate? Yes ☐ No ☐

Is the information parent friendly? Yes ☐ No ☐

Briefly list suggestions for improving the messages:



an I choose ~~which treatable~~ what conditions my baby is creened for?

o, all 17 treatable conditions are screened for at once and cannot be creened for individually

you would like additional screening talk to your doctor or midwife about ore options after you get the newborn blood spot screen done

~~he treatable conditions screened for are carefully chosen to make sure~~ ~~at your baby's health will be improved from having the screen done and~~ ~~etting early treatment~~

you have concerns about a specific condition in your family you would e your baby screened for, please talk to your doctor or midwife.

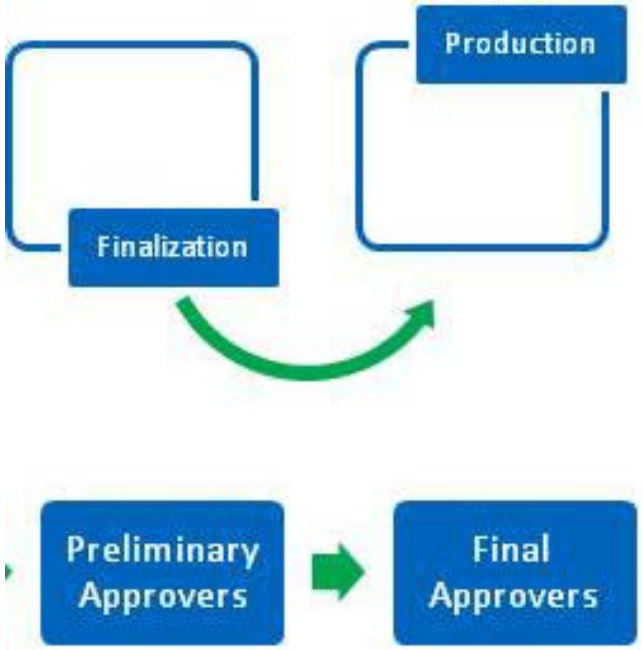
	Yes	No		
Clinically Accurate	10	1	Gloria	
Parent Friendly	12			

Feedback

- No, all treatable conditions are screened for at once. The ~~cannot be screened for individually.~~
~~The middle bullet here doesn't really answer the question above. Maybe add a separate question, "Can I get additional screening done for other treatable conditions no covered by the newborn blood spot screening?"~~
~~The last bullet implies that all babies will have their health improved by participating. Not sure it's relevant to the question.~~
- ? typo in the first bullet. Perhaps a new sentence after 'once' or a semi colon?
- Please talk to your doctor or midwife about any concernns you have about conditions in your family.
~~first bullet is a bit awkward in reading, maybe just needs some punctuation between once and they~~
- For first bullet
- If you do not want testing for some of the 17 treatable conditions , talk to your doctor or midwife about different testing.

The second bullet is OK. Delete third bullet. This info

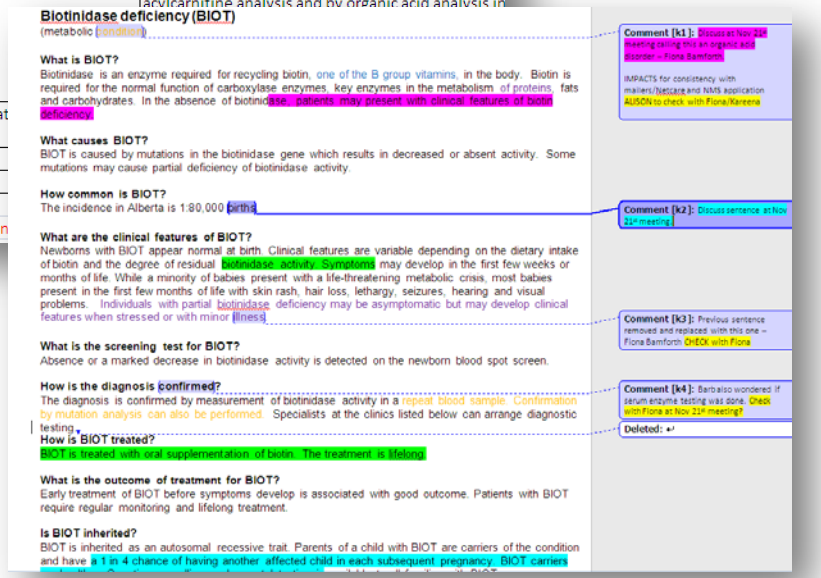
Finalization and Production



- Communicate timelines to endorser, approver levels
- Use rounds of approval, limited revisions
- Work backwards from deadline
- Finalize/approve layout
- Copy edit content, then put into approved layout

Colour Coding and Endorsement

	Long Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) deficiency		
2	Endorser	Concern for discussion	Revision
3	NAMES	1. How is LCHAD deficiency treated? Consistency edit - Treatment is lifelong	1. Not revised as consistent with other sheets
4	NAMES		
5	NAMES	1. What are the clinical features? Suggest "Children may also have developmental delay, poor weight gain, neurological problems, liver disease and cardiomyopathy. 2. What is the screening test? Suggest "a specific pattern of metabolites is detected on the newborn blood spot screen." 3. How is the diagnosis confirmed? Suggest "The diagnosis is confirmed by detecting specific metabolites in urine or on blood acylcarnitine analysis.	1. Changed - see sheet 2. Changed - see sheet (took out "increased long chain fatty acid metabolites are detected..." 3. Changed - see sheet (took out "...finding incresed long chain fatty acids on blood acylcarnitine analysis and by organic acid analysis in
6	NAMES	1. Comment: Suggestion perhaps insert word: Increased long chain "hydroxy" fat metabolites...	
7	NAMES		
8	NAMES		
9			
10	Karen	1. What are FAOD? This section is different than CUD. - see CUD excel section un	



Biotinidase deficiency (BIOT)
(metabolic condition)

What is BIOT?
Biotinidase is an enzyme required for recycling biotin, one of the B group vitamins, in the body. Biotin is required for the normal function of carboxylase enzymes, key enzymes in the metabolism of proteins, fats and carbohydrates. In the absence of biotinidase, patients may present with clinical features of biotin deficiency.

What causes BIOT?
BIOT is caused by mutations in the biotinidase gene which results in decreased or absent activity. Some mutations may cause partial deficiency of biotinidase activity.

How common is BIOT?
The incidence in Alberta is 1:80,000 births.

What are the clinical features of BIOT?
Newborns with BIOT appear normal at birth. Clinical features are variable depending on the dietary intake of biotin and the degree of residual biotinidase activity. Symptoms may develop in the first few weeks or months of life. While a minority of babies present with a life-threatening metabolic crisis, most babies present in the first few months of life with skin rash, hair loss, lethargy, seizures, hearing and visual problems. Individuals with partial biotinidase deficiency may be asymptomatic but may develop clinical features when stressed or with minor illness.

What is the screening test for BIOT?
Absence or a marked decrease in biotinidase activity is detected on the newborn blood spot screen.

How is the diagnosis confirmed?
The diagnosis is confirmed by measurement of biotinidase activity in a repeat blood sample. Confirmation by mutation analysis can also be performed. Specialists at the clinics listed below can arrange diagnostic testing.

How is BIOT treated?
BIOT is treated with oral supplementation of biotin. The treatment is lifelong.

What is the outcome of treatment for BIOT?
Early treatment of BIOT before symptoms develop is associated with good outcome. Patients with BIOT require regular monitoring and lifelong treatment.

Is BIOT inherited?
BIOT is inherited as an autosomal recessive trait. Parents of a child with BIOT are carriers of the condition and have a 1 in 4 chance of having another affected child in each subsequent pregnancy. BIOT carriers

Comment [k1]: Discuss at Nov 21st meeting cause this an organic acid disorder – Fiona Bamforth

IMPACTS for consistency with mailers//betcare and NMS application ALISON to check with Fiona/Kareena

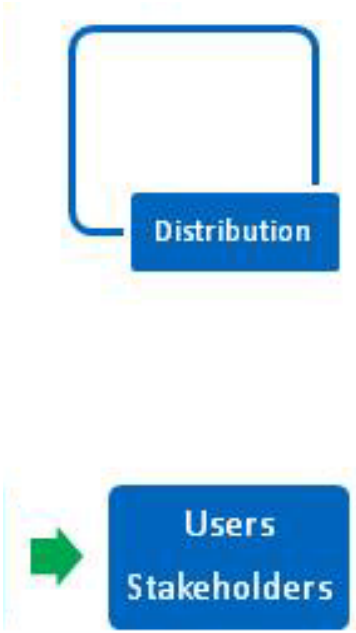
Comment [k2]: Discuss sentence at Nov 21st meeting

Comment [k3]: Previous sentence removed and replaced with this one – Fiona Bamforth CHECK with Fiona

Comment [k4]: Barb also wondered if serum enzyme testing was done. Check with Fiona at Nov 21st meeting?

Deleted:

Distribution



- Develop communication plan to audiences, users, stakeholders
- Create access plan “push or pull” (e.g., web pages, print ordering)
- Plan for version control (e.g., dates and #s)
- Plan for future updates (e.g., receiving feedback after finalization)
- Distribute and start again!

Alberta Health Services

Newborn Metabolic Screening Program

Communication and Access

Alberta Health Services Newborn Metabolic Screening Program

NMS Program Resource Order Communication:

What & Why

A "What"	A "So What" & or "Now What"
To inform pathway partners of the blood spot card and envelope order process	The NMS requisition order and distribution process has changed to an on-line ordering process
NMS Program email push with link to NMS Program external page	NMS Program collectors will access the collection catalogue from the NMS Program external page
[Click here to enter a purpose or objective of the communication. For example to tell people the clinical policy suite is available online.]	[Click here to enter a why people need to know or care about the "what". For example, people can now view the clinical policy to know what practice changes they need to implement.]

Who

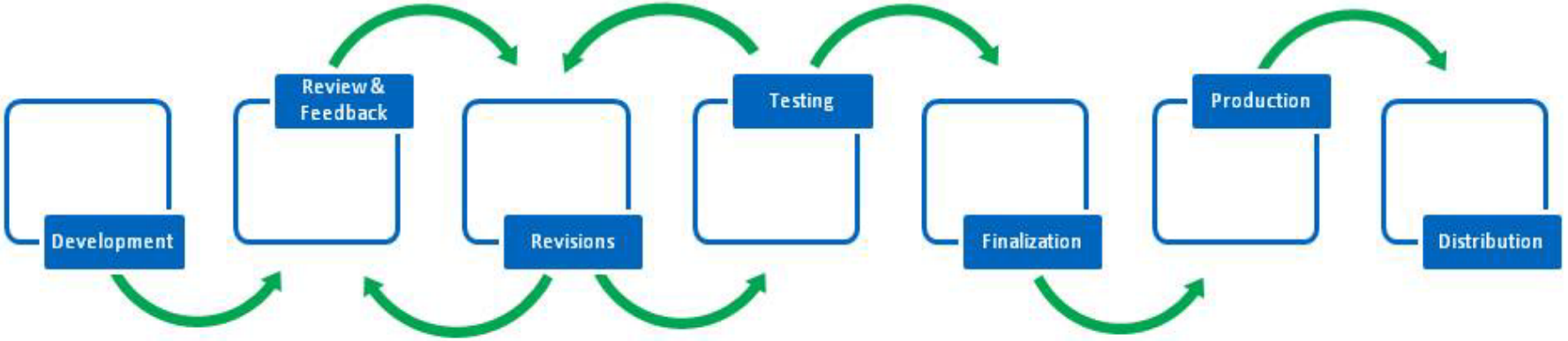
Service Area	Affiliate Status	Key Contact	Source – contact info
In-patient & Out-patient labs	DynaLIFEdx	Rob Cambell Assistant Manager, Materials Management, DynaLIFEdx rob.campbell@dynalifedx.com	Master Stakeholder XXX
In-patient & Out-patient	CLS	Shelley Relf Supervisor Regional Records Management Shelley.relf@cls.ab.ca	Master Stakeholder
Calgary Zone PH/postpartum units		Margaret Fung Educational Resource & Pamphlet Clerk Health Link Margaret.fung@albertahealthservices.ca **PLC** Unit 33 PP, Unit 35B NICU, Unit 31 Pediatric Child's Health **FMC** Unit 52 PP, Unit 55 NICU) **RGH** Unit 63 NICU, Unit 64 PP, Women's Specialty Clinic Unit 62A L/D **ACH** NICU **Public Health** (South, North Hills, East)	Master Stakeholder ? Still send to Marilyn Young for Calgary rural PHNS

May 31, 2013 Page 1 of 4

Alberta Health Services

Newborn Metabolic Screening Program

Implementation Steps: *From Development to Distribution*



Communication
Knowledge Exchange
Evaluation

Adapting the approach

- Where ever resources are created, adapted, developed and/or disseminated
- Multiple community health nursing practice settings
  - public health
  - home health
  - midwifery
  - First Nations
  - health education

Thank-you!

Acknowledgements: Courtney Felker, Melissa Smokeyday