Working Group Objectives

- Propose a development and approval process for establishing the minimum dataset collected for each disease / disease grouping
- Develop a tool for documenting the disease-specific minimum dataset
- Define data elements common to all diseases
- Define a schedule for review of all the existing provincial case report forms
Provincial Case Report Form
Development and Approval Process

Step 1

Establish Working Group
Working Group

- Recommend that existing groups be leveraged or augmented where possible (e.g. enteric policy WG, STIBBI)
- Minimum composition:
  - 1 representative from each Health Authority, including FNHA
  - 1 representative from BCCDC
  - Among the group, at least one member should be a Medical Health Officer, epidemiologist, public health nurse and/or EHO.
  - End users of the provincial case report forms should be consulted in the process, if different from the above (e.g. GPs).
- Optional:
  - Groups may seek consultation from BCPHMRL medical microbiologists on laboratory variables, as needed, and from MOH staff, where appropriate.
Provincial Case Report Form Development and Approval Process

Step 1
- Establish Working Group

Step 2
- Articulate surveillance / public health management objectives
  - If new CRF, have CDP review and approve objectives prior to Step 3

BC Centre for Disease Control
An agency of the Provincial Health Services Authority
Establish Objectives

- Disease-specific objectives may be related to surveillance, public health management, or clinical management
- New CRFs, or those with major changes to surveillance, must have the objectives reviewed and approved by CD Policy prior to defining variables for collection
Provincial Case Report Form Development and Approval Process

Step 1
Establish Working Group

Step 2
Articulate surveillance / public health management objectives
If new CRF, have CDP review and approve objectives prior to Step 3

Step 3
Define variables to support surveillance, public health management or clinical management
• Link to objectives
• Include dataset common to all diseases
• Include pre-defined datasets for VPD, TTI and neonatal/congenital, if applicable
Define Variables

• To be included in a CRF, a variable must support at least one of:
  ▪ Surveillance
  ▪ Public Health Management
  ▪ Clinical Management

• Each variable is tied explicitly to a main purpose (above) and to the specific objective it supports
Pre-defined Variable Sets

Working groups given pre-defined dataset upon which they will layer any group or disease-specific data requirements

- Data Common to All Diseases (complete)
- Group-specific data requirements
  - To be developed by WGs, as appropriate. For example:
    - Data Common to VPDs
    - Data Common to TTIs
    - Data Common to neonatal/congenital infections
  - Will be approved by CD Policy and made available for other disease-specific working groups
Minimum Dataset Definitions

Diseases with Provincial CRFs

- Data Common to All Diseases (Pre-defined)
- Group-specific variables, if applicable e.g. VPD
- Disease-specific variables identified by Working Group

Diseases without Provincial CRFs

- Data Common to All Diseases (Pre-defined)
- Group-specific variables, if applicable e.g VPD

Minimum Dataset for Disease / Disease Group
# Data Common to All Diseases

<table>
<thead>
<tr>
<th>Last Name</th>
<th>Causative Agent</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Name</td>
<td>Classification</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>Report Date (received)</td>
</tr>
<tr>
<td>Gender</td>
<td>Test Name</td>
</tr>
<tr>
<td>Health Care Number (PHN)</td>
<td>Specimen</td>
</tr>
<tr>
<td>Health Region</td>
<td>Collection Date</td>
</tr>
<tr>
<td>City</td>
<td>Result / Interpreted Result</td>
</tr>
<tr>
<td>Postal Code</td>
<td>Onset date or closest proxy</td>
</tr>
<tr>
<td>Disease</td>
<td>Aboriginal Data Standard</td>
</tr>
</tbody>
</table>
Recommendations

• Evidence review be conducted by the working group to identify specific risk factors to be collected on the form

• General quality review be conducted of the variables collected on existing CRFs
Assessment Tool

Assessment Tool\Provincial CD Case Report Form
Assessment Tool 2015 09 10.xlsx
# Sharing Data

The tool specifically captures which data is required to be shared at the provincial level.

<table>
<thead>
<tr>
<th>Data element collected</th>
<th>Rationale for collection</th>
<th>Relates to which Objective from Step 2</th>
<th>Clinical Management^</th>
<th>Public Health Management</th>
<th>Data needed provincially?*</th>
<th>Surveillance</th>
<th>Data needed provincially?*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last Name</td>
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</tbody>
</table>

^ Assumption that data collected regionally for clinical management is never needed provincially

* Data needed at the provincial level is to be shared using Panorama
Provincial Case Report Form Development and Approval Process

Step 1: Establish Working Group

Step 2: Articulate surveillance / public health management objectives
If new CRF, have CDP review and approve objectives prior to Step 3

Step 3: Define variables to support surveillance, public health management or clinical management
- Link to objectives
- Include dataset common to all diseases
- Include pre-defined datasets for VPD, TTI and neonatal/congenital, if applicable

Step 4: Create or update the provincial CRF

Step 5: Submit CRF and CRF Assessment Tool to CD Policy for approval
Decision and Next Steps

• Recommend CD Policy acceptance of process and tool
• Recommend including the package in the new Surveillance chapter of the CD manual
  ▪ Process
  ▪ Assessment form
  ▪ Core dataset common to all diseases
  ▪ Group-specific datasets, as developed
• Recommend CD Policy confirm that aboriginal data standards (currently included in the ‘data common to all diseases’) are to be collected for all RCDs
• Working groups to use process to review existing CRFs over the next 1.5 years
# Schedule of Provincial CRF review

<table>
<thead>
<tr>
<th>Year</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>June</th>
<th>Jul</th>
<th>Aug</th>
<th>Sept</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td></td>
<td>Hep B/C</td>
<td>TB</td>
<td>SOS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diphtheria</td>
<td>AIDS CJD</td>
<td>HIV</td>
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<td></td>
<td></td>
<td></td>
<td>HIB Measles, Mumps, Rubella Meningo, invasive Pneumo, invasive iGAS Strep, group B Tetanus</td>
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</tr>
<tr>
<td>2016</td>
<td>Enterics Shellfish-related illness</td>
<td>Pertussis</td>
<td>Chlamydia Syphilis Gonorhea Lymphogranuloma ma venereum</td>
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<td></td>
<td>Vectorborne Zoonotic</td>
</tr>
</tbody>
</table>

*Calendar months represent the anticipated start date of the Minimum Dataset review process for each disease or disease grouping*

Not yet scheduled:
- SARI
- Hepatitis A
# Working Group Members

<table>
<thead>
<tr>
<th>Michelle Murti, FHA</th>
<th>Jason Wong, BCCDC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sherry Baidwan, FHA</td>
<td>Bonnie Henry, MOH</td>
</tr>
<tr>
<td>Monika Naus, BCCDC</td>
<td>Reka Gustafson, VCH</td>
</tr>
<tr>
<td>Laura MacDougall, BCCDC</td>
<td>Margot Smythe, VCH</td>
</tr>
<tr>
<td>Eleni Galanis, BCCDC</td>
<td>Dee Hoyano, VIHA</td>
</tr>
</tbody>
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