Appropriateness of Care Framework: Toolkit







Implementation Process for Appropriateness of Care Methodology

Once the targeted clinical area of focus has been selected, the following implementation steps may be applied to the project.

1. Establishment of a Clinical Development Team

- Identify the physician and administrative lead who will support and oversee the work
- Identify key "clinical content expert" individuals (other physicians, healthcare professionals, patients, researchers, etc.) who will be involved
- Identify supporting resources (e.g. analyst support)
- Identify roles, responsibilities, and time commitments required of members
- Develop a communication strategy to engage development team members (roles and responsibilities, remuneration etc.)
- Begin to identify evidence based guidelines and literature that exists within the clinical area of focus
- Establish a timeline for establishing the development team

2. Identify improvement opportunities within the clinical area of focus

- Map the current state for the selected process and identify areas where there is variation or places for improvement exist
- The Clinical Development Team prioritizes the project areas and considers whether there is opportunity to address more than one project or agree on one project
- Set a timeline with an expected date for when the Clinical Development Team should come to an agreement on what their project focus will be
- Identify techniques for prioritizing projects if there is not a consensus within the group

3. Establish common agreed practices, tools and data to measure the outcomes and processes

 Based on the current state, develop a common agreed practice or future state, allowing for variation where data will be collected to further understand the impact of such variation on patient outcomes

 Discuss importance of measurement to support this work and determine outcome, process and input measures. Include discussion on the importance of Patient Reported Outcome Measures and Shared Decision-Making

4. Trial the common agreed practices and clinical support/data collection tools

- Develop a plan for communication and engagement
- Develop tools that can collect required data information, but that can be integrated into the workflow and support clinical decision making
- Identify the scope of the project, for example will this be trialed in one practice group, city, one RHA, or the whole province etc.
- Implement the agreed practice and tools and complete Plan, Do, Check, Action (PDCA) cycles to understand effectiveness

5. Monitoring, evaluation and revisions

- Develop a learning forum that will review the PDCAs, monitor outcome data and provide reports back to the development team on the common agreed practice. The forum will facilitate required revisions to tools, process, common agreed practice etc.
- Replicate to other clinical areas or to other organizations (e.g. facilities or health regions to replicate the project)
- In the new region, facility, or organization where replication is underway, implement the common agree practice, tools, and data collection that were developed in the implementation phase.
- Continue to monitor, evaluate, and revise, data, tools and the common agreed practice.

Process and Criteria for Selecting Appropriateness of Care Projects

- 1. Identify potential clinical areas or opportunities for improving Appropriateness of Care within your organization. You may consider the following information when identifying potential areas:
 - Are there any improvement ideas generated by clinicians?
 - Are there high volume clinical processes/cases for which variation has been identified by clinicians or the local system?
 - Are there Appropriateness of Care issues in the targeted regional and health system priorities/hoshins/outcomes areas that need to be addressed?
 - What are the emerging healthcare issues at the regional, provincial and national level?
 - Is there any new evidence from research that needs to be embedded into clinical practices?
- 2. Identify key elements for the selection criteria that can be used for selecting Appropriateness of Care projects for the coming year (s) (See the Table 1 for suggested selection criteria)
- 3. Rank each element of the criteria on a scale of 1 5 ('5' being the highest and '1' being the lowest) based on the level of importance and potential impact.
- 4. Assign the weighting scale to individual elements on a scale of 1 10 ('10' being the highest and '1' being the lowest) based on the relative importance (See the suggested weights listed below in Table 1).
- 5. Calculate the scores of individual elements (multiplying the rank with the weight) and then add them all to get the total score for an option.
- 6. Follow the same process to obtain the total scores for the other options and then compare the scores of all the options to make a decision (See Table 2).

Table 1: Selection Criteria for Appropriateness of Care Projects

	Rank (1-5) (5 being the highest and 1 being the lowest)	Weighting	Score
Impact on other health			
regions/organizations (opportunities to			
collaborate with other			
regions/organizations)			
Affects a significant portion of the patient			
population that your organization serves			
Aligned with health system			
priorities/regional priorities (i.e. hoshins			
and outcomes)			
Potential for quick wins (easy to			
implement)			
Relatively low costs for implementation			
(low investment)			
Significant impact on quality of patient			
care and safety			
High cost, high volume			
procedure/treatments or both			
Ability to leverage existing structures to			
support clinical change (e.g. provider			
education/training and knowledge of QI			
methodologies)			
Administrative leadership (Senior			
Leadership) support			
Availability of clinician			
leadership/champions			
Evidence-based information/tools			
available			
Availability of data to identify issues and			
measure the outcomes			
Total Weighted Score			

Suggested Weights (Maximum Score: 320):

- Impact on other health regions/organizations (opportunities to collaborate with other regions and organization X 5
- Affect a significant portion of patient population that your organization serves:
 X 5
- Aligned with health system/regional priorities (i.e. hoshins and outcomes) X 5
- Potential for quick wins (easy to implement) X 2
- Low cost of implementation (low investment) X 2
- Significant impact on quality of patient care and safety X 10
- High cost, high volume procedures/treatments or both X 5
- Ability to leverage existing structures to support clinical change X 5
- Administrative leadership (Senior Leadership) support X 5
- Availability of clinician leadership/champions X 10
- Evidence-based information/tools available X 5
- Availability of data to identify issues and measure the outcomes X 5

Table 2: Total Weighted Scores for Individual Options

	Option A	Option B	Option C	Option D
Total Weighted Score				

- 7. Once one or two clinical areas are selected, conduct an e-scan and literature reviews to identify available best practices and tools, and what other jurisdictions and organizations are doing to address inappropriate care issues in the selected clinical areas
- 8. Develop business cases for the selected areas using the information collected from the e-scan and literature reviews.
- 9. Obtain feedback on the business cases from committees or working groups that are part of your organization's Appropriateness of Care Governance and Decision Making structure (e.g. the provincial Appropriateness of Care program has the Appropriateness of Care Steering Committee that oversees the entire program) individual regions and organizations may have different Governance and Decision Making structure for Appropriateness of Care.
- 10. Submit the business cases to appropriate the senior leadership team (SLT) within your organization for their review and approval.

Shared Decision-Making: Involving Patients and Families in Treatment Decisions

What is Shared Decision-Making?

Shared Decision-Making (SDM) is a collaborative decision making process shared between patients and their clinicians to make mutually agreed upon healthcare decisions using evidence-based information, patient's needs, values, preferences, and cultural/religious beliefs and background. It requires a two-way information exchange and deliberation between the two parties.

Does Shared Decision-Making Applicable to Any Care Conditions?

SDM is most appropriate for care conditions where there is more than one medically reasonable treatment option (including status quo, "do nothing") with no clear best choice for outcomes. The treatment options for these conditions involve significant tradeoffs in the patient's quality or length of life. Many clinical situations, including cancer care, elective surgery, screening, chronic disease conditions (life style change, medication use), end of life care, mental health, etc., have more than one treatment option. For such situations, the right choice will depend on a patient's own needs, preferences, and values supported by clinician's recommendations or opinions. Providing complete, evidence-based information about different treatment choices can help patients make informed decision.

What are the Components of Shared Decision-Making?

A typical SDM process uses decision support tools designed to facilitate SDM by:

- Providing patients with up-to-date, evidence-based information about their condition and treatment options, including benefits, harms, outcome probabilities and scientific uncertainties;
- Helping patients clarify values and preferences they place on the benefits and harms;
- Guiding patients in deliberation to improve patient involvement in the decision making process; and
- Helping patients make an informed decision.

There are two types of decision support tools: Patient Decision Aids (PtDAs) and Decision coaching/counseling. It is important to understand that decision support tools are not to "replace" counseling from a clinician but to "complement" the clinician's counseling by helping patients prepare to engage in the decision making process and to make informed, value-based decisions with their clinician. They are not intended to advise patients to choose one option over another (IPDAS Collaboration)

Patient Decision Aids (PtDAs)

There are numerous PtDAs developed in a variety of formats from a simple one-page sheet that outlines treatment choices to more detailed pamphlets, booklets, computer programs, DVDs or interactive websites that include filmed interviews with patients and professionals. PtDAs are different from traditional patient information/education materials and clinical guidelines in that they explicitly state what decision is to be made; use the best available evidence to qualify benefits and harms; and help patients deliberate about the options based on their values and preferences (Coulter & Collins, 2011; Deyo, 2001).

Decision Coaching

Decision coaching refers to the process by which a knowledgeable health professional provides a patient with individualized, nondirective guidance to meet decision-making needs in preparation for consultation with the clinician (Stacey et al, 2012). Decision coaching is considered a useful adjunct to clinician counseling, especially when a patient experiences decisional conflict - a state of uncertainty in identifying the best course of action when a patient is confronted with decisions involving risk or uncertainty of outcomes (O'Connor, 1995).

What does a Typical Shared Decision-Making Process Look Like?

The following steps have been identified in the inter-professional SDM (IP-SDM) model developed by the Ottawa Hospital Research Institute. These steps maybe adapted for the routine clinical practices in Saskatchewan.

- 1. Make it clear to the patient that a decision need to be made;
- 2. Exchange information about the options, benefits, and harms (PtDAs can be used to provide this information. They can be provided during or after the consultation);
- 3. Clarify patient's values and preferences (there are questionnaires developed to help clarify patients' values and preferences);
- 4. Discuss feasibility of the options (e.g. accessibility and costs);
- 5. Arrive at mutually agreed upon decision (at this step, if the patient and/or families are still not comfortable with decision making, he/she may delegate decision making role to his/her clinician); and
- 6. Implement the chosen option (for chronic condition management, patients and/or families may require guidance for implementing).

SDM conversations can be provided by any clinicians, including physicians, nurse practitioners, and other healthcare professionals, depending on clinical settings. However, one of the biggest perceived barriers identified by physicians to implementing SDM was "time constraint". For instance, an average physician-patient

consultation time is 15 minutes. During this 15 minutes, physicians may have to do multiple tasks, including taking a medical history from the patient, performing a physical examination, making a diagnosis, reviewing concerns, writing a prescription, etc. It can be challenging for physicians to be engaged in the full process of SDM.

To address this time constraint, some organizations or clinical practices have utilized other healthcare professionals, such as nurses, dietitians, social workers, physiotherapists, pharmacists or other appropriate practitioners to provide PtDAs and decision coaching to the patients. In Saskatchewan, patients considering hip or knee replacement surgery are referred to a multidisciplinary clinic where patients receive PtDAs and decision coaching. The designated decision coach creates a decision summary, including patient clinical condition, patient's values and preferences. This decision summary is forward to the surgeon to be used during the next consultation with the patient.

Why Do We Want to Implement Shared Decision Making in Saskatchewan?

There has been a growing interest in SDM around the world as a means of delivering the appropriate treatment to patients through information sharing and empowering them to participate in their own care and decision making. However, there is a significant gap between what patients want and what clinicians think they want in terms of treatment. According to systemic researches conducted on SDM, patients choose differently when they are fully informed about treatment options with their benefits and risks (Stacey et al, 2011). A treatment decision is a function of both medical diagnosis and preference diagnosis. Misdiagnoses of patients' preferences and values can affect not only health outcomes and wellbeing of patients but also costs of the healthcare service delivery (Mulley et al, 2012). There is evidence suggesting that SDM provides benefits not only to patients, but also to providers and the healthcare system:

- **For patients**, SDM improves patients' knowledge of treatment options, satisfaction with the treatment choice and their adherence to their treatment regimes.
- **For providers,** SDM improves quality of consultation and increases trust in the patient-clinician relationship without increasing consultation time.
- **For the system**, SDM can potentially reduce unwarranted clinical variations and ensure that the care patient received is appropriate (i.e. address overuse, underuse, and misuse of healthcare services).

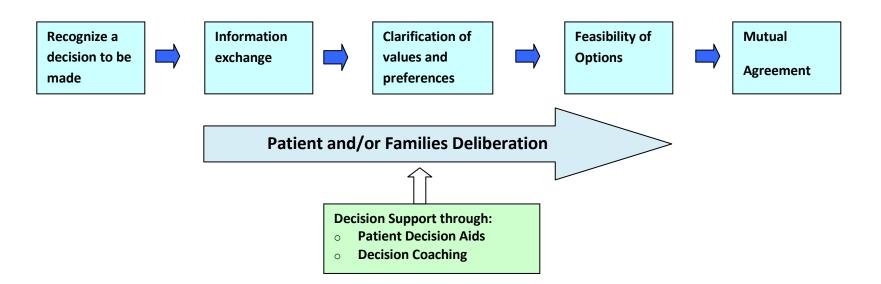
What are the Potential Clinical Areas for Implementing Shared Decision Making?

As part of the Saskatchewan Surgical Initiative, SDM has been implemented in the surgical pathways: hip and knee replacement, prostate cancer treatment, and treatment of pelvic floor conditions.

SDM can be embedded into various other clinical areas within:

- Cancer care;
- Elective surgery;
- Cancer screening (e.g. breast cancer, prostate cancer, colorectal cancer, etc.);
- Chronic disease management (e.g. prescription medications);
- Mental health (depression, anxiety, schizophrenia, etc.)
- Pregnancy and Child Birth (e.g. prenatal testing, child birth, breastfeeding, etc.);
 and
- End of life care (place of care at the end of life at home or at a facility, treatments that prolong the life, long-term feeding tube placement for elderly patients, planning care for critically ill patients in the Intensive Care Unit (ICU), Cardiopulmonary Resuscitation (CPR), life support, artificial hydration and nutrition, etc.)

Shared Decision-Making



Roles of Patients and/or Families

- Understand the information provided by their clinician (ask questions to the clinician if they don't understand the information).
- Share personal information about their life style, cultural backgrounds and beliefs, values, and preferences that may affect treatment decisions with their clinician.
- Weigh their values and preferences regarding the potential benefits and harms associated with treatment options.

Roles of Clinicians

- Understand the information provided by patients and/or families (ask questions if he/she understands the information) and allow them to exchange their knowledge on other alternative treatment options that are not included in the information (e.g. herbal therapy, acupuncture etc.).
- Ensure that they have fully understood the information and if necessary, provide decision counselling to support them in making decisions.
- Elicit their values and preferences to each option (i.e. what is most important to them).

How to Embed SDM into Appropriateness of Care Projects?

SDM can be incorporated into any Appropriateness of Care projects as long as the targeted clinical areas have more than one treatment option. The following tips can be considered when embedding SDM into Appropriateness of Care projects:

- When the Clinical Development Team maps a clinical flow or patient flow, it is critical to:
 - ➤ Identifying decision points where PtDAs and SDM can be introduced to patients; and
 - ➤ Identifying barriers and facilitators to implementing PtDAs.
- Identify an appropriate PtDA from existing PtDAs²⁵ or develop a new PtDA and decision support tools (e.g. Ottawa Generic Decision support tool, SURE tool);
- Create a system for PtDA distribution (e.g. who and how to provide PtDAs to patients and/or families, how to ensure they received PtDAs, etc.)
- Determine roles of each healthcare professional (e.g. physician, nurses, physiotherapist, dietician etc.) and staff (e.g. administrative staff, case manager, receptionist, etc.) in embedding SDM in clinical workflow
- Identify progress and outcome measures for SDM and embed them into clinical workflow
- Embed the data as well as PtDAs and decision support tools in the electronic medical record (EMR) to make it easier for clinician to incorporate SDM into consultations with patients.

Potential Measures for Shared Decision Making

Patient Outcomes Indicators

For the patient outcomes, there is evidence that SDM increased patient knowledge of treatment options, reduced their decisional conflict, and increased their satisfaction with the treatment choices. The following measurement tools developed by the Ottawa Hospital Research Institute (OHRI) can be used to measure quality of PtDAs, as well as impacts of PtDAs on patients' knowledge, decisional conflict, and confidence: http://decisionaid.ohri.ca/eval.html.

https://www.healthwise.net/saskhealthlineonline/Content/StdDocument.aspx?DOCHWID=share

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²⁵ Many high performing healthcare organizations around the world, including the National Health Services (NHS) in UK and Mayo Clinic in US, have developed patient decision aids (PtDAs) in various clinical conditions. In Canada, the Ottawa Hospital Research Institute website provides numerous existing PtDAs. Also, US non-profit organizations, such as Healthwise and the Informed Health Decision Making have developed various PtDAs and provide them to various healthcare organizations in US. Currently, patients in Saskatchewan can access various PtDAs through the Healthline Online developed by Healthwise:

Patient Outcomes / Decision Comfort (SURE tool)	Indicators
Patients' knowledge of treatment	# of patients who reported that they understood
choices	the benefits and risks of treatment options
	# of patients who reported that they were clear
Patient's values	about which benefits and risks matter most to
	them
Support for patients to make a	# of patients who reported that they had enough
decision	support and advice to make a choice
Containte of the desiries	# of patients who reported that they felt sure about
Certainty of the decision	the choice they made for themselves
Total Score	• # of patients who scored 4/4 for these items
Patient Outcome: Satisfaction	Indicators
Patient satisfaction with the	# of patients who were satisfied with the decision
decision and/or decision making	and/or decision making process
process	
D	# of patients who do not feel regret about the
Decision regret	decision made

Provider Outcomes Indicators

In terms of provider outcomes, research indicates that SDM improved the quality of consultation without increasing the consultation time. The following indicators can be used as SDM outcome measures:

Provider Outcomes	Indicators	
Quality of consultation	 # of patients who indicated their clinician involved them in SDM # of consultations in which SDM was observed 	
Clinician and patient consultation time	Amount of clinician and patient consultation time spent for SDM compared to usual consultation time	
Clinician satisfaction	# of clinicians reported that they are satisfied with SDM	

References:

Coulter A, & Collins A. (2011). *Making shared decision-making a reality: No decision about me, without me.* The King's Fund.

Deyo RA, Cherkin DC, Weinstein J, Howe J, Ciol M and Mulley AG. *Involving Patients in Clinical Decisions: Impact of an Interactive Video Program on Use of Back Surgery*. 2000. Medical Care. 38(9): 959-969.

Mulley A, Timble C and Elwyn G. *Patients' Preferences Matter: Stop the Silent Misdiagnosis*. 2012. The King's Fund.

Stacey D, Kryworuchko J, Murray AM, Mullan S and Légaré F. *Decision Coaching to Prepare Patients for Making Health Decisions: A Systematic Review of Decision Coaching in Trials of Patient Decision Aids.* 2012. Medical Decision Making. Vol 32(3): E22-32

Stacey D, Bennett LC, Barry JM, Col FN, Eden BK, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F and Thomson R. *Decision Aids for People facing Health Treatment or Screening Decisions*. Cochrane Database of Systematic Reviews. 2011. Issue 10.

Data Development and Measurements for Appropriateness of Care Projects: Data Collection, Analysis and Reporting

Introduction

The purpose of this document is to highlight considerations when trying to identify and access data to support Appropriateness of Care work.

The value of clinical data to drive quality improvement and change is well established: "We can't change what we don't measure". Timely tracking and review of patient outcomes over time and visual display of the information can help identify: where outcomes are being optimized and where they are not; where change in outcomes is a result of random variation or true system change; and where and how processes can be modified for positive impact.

Dr. Brent James (Intermountain Healthcare) provides an example of outpatient management of anticoagulation and the importance of visually tracking patient outcomes over time as illustrated in **Figure 1** on page two.

Three clinicians in an outpatient clinic managed warfarin but none measured the impact over time of changing the dosage on the desired outcome (INR). Patient LL had their INR checked regularly and it was found to fluctuate. In response to the fluctuations and the INR value falling out of the desired range, the physician would modify the dose. This continued for some time with modifications to the medication dose occurring frequently in response to each INR value. After many dosage alterations and INR fluctuations the physician considered whether there was an appropriate dosage amount and how he could know when to modify the dose to optimize his patient's INR value (outcome). He graphed his patient's INR values over time and annotated his chart with the warfarin dose changes. By graphing the data he could see the trends in the impact of the dosage changes on the INR value and better understand when it was appropriate to change the dosage.

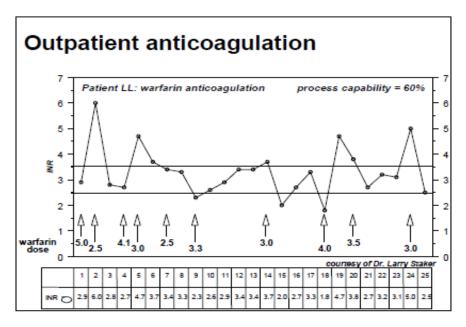
Experience has shown that clinicians are motivated by both generic data from the literature and more localized data highlighting their own patients and practices.

Health data exists in a variety of datasets and formats in Saskatchewan. Section 2 of this document outlines a few considerations when choosing to use existing data to support Appropriateness of Care work. However, in many situations the clinical data required to support clinical quality improvement is not available. In these cases new datasets are needed. Section 3 of this document provides guidelines for measurement system design and creating new datasets.

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The steps in identifying and designing data correspond to the steps in the Appropriateness of Care framework. Where appropriate these links are highlighted in the document.

Figure 1



Intermountain Healthcare

Context Setting (pre-Project) Data

- Identify, within the patient-centered clinical area of focus, preliminary data that could provide some context:
 - > Review key literature to identify relevant variables or metrics
 - Discuss key data with development team clinical lead
- Consider where this data will be obtained
 - ➤ Provincial administrative databases. (See Appendix I for a list of databases that the Health Quality Council has access to.)
 - o As of June 2015, eHealth Saskatchewan is currently creating a catalogue of Saskatchewan datasets (See eHealth Saskatchewan for more information).
 - ➤ Health organization data (e.g. Saskatchewan Cancer Agency, Public Health Observatory).
 - Clinical registries or project databases (e.g. Saskatchewan Spine Pathway).
 - Published Saskatchewan literature on the topic
 - Unpublished research with relevant data (e.g. medical student project).
 - Other published reports (e.g. CIHI reports)

- Consider how the data will be analyzed and shared at the development team meeting
 - ➤ How many years of data are important to share?
 - ➤ What stratifications and potential comparisons are needed (e.g. by health region? by physician? by facility? etc.)
 - ➤ Are there particular sub-cohorts of patients of interest?
 - ➤ Within the database where this data is housed, what data codes should be considered? (e.g. What specific ICD-10-CA codes would be needed from the Discharge Abstract Database)?
 - ➤ How should the data be presented? (tables or graphs)?
- Consider what types of privacy documents are needed in order to access, analyze, and share this data, including data sharing schedules, ethics and patient consent forms. Key contacts for information related to these are (this is not an exhaustive list):
 - University of Saskatchewan Ethics (http://research.usask.ca/for-researchers/ethics/)
 - University of Regina Ethics (http://www.uregina.ca/research/REB/main.shtml)
 - Saskatoon Health Region Operational Approval;
 (Shawna.weeks@saskatoonhealthregion.ca)
 - Regina Qu'Appelle Health Region Operational Approval; (http://www.rqhr-rps.ca/research-ethics/)
 - > Saskatoon Health Region Enterprise Risk Management (re: Data Sharing)

Project Data

Data to track effectiveness of changes

Within a project, clinicians may choose to trial a change in practice to improve patient outcomes, better align with evidence based care or agreed upon standards, and reduce variation. It is important to track the effectiveness of such change to understand how it impacts outcomes and where further change may be needed. If there is variation in how patients are treated within the practice, the impact of such variation on outcomes need to be captured.

The following section outlines a process for identifying metrics to track effectiveness. The detailed data that is often needed to highlight effectiveness and report outcomes may not be available within existing Saskatchewan datasets. New data sets may need to be developed.

Steps for identifying key metrics

Use developed process maps (a key step in helping the development team identify projects within their clinical area of focus to work on) to identify key outcome, process, and input metrics that need to be captured

- Outcome Metrics: Clinical outcome information provides a means to evaluate the
 effectiveness of the treatments in achieving their stated goals. Correspond
 directly to the outcomes tracked in a randomized control trial. Outcomes fall
 into three categories:
 - Physical outcomes: Correspond to the traditional ideas of quality and equate to 'medical outcomes'
 - > Service (satisfaction) outcomes: Parallel to health care access and track consumers' subjective perceptions of the interaction between a provider and a consumer.
 - ➤ *Cost outcomes:* The resources that a process consumes as it operates.
- *Process Metrics*: Measurable factors that track a process' important outputs include:
 - ➤ *Process Metrics:* Represent critical performance steps that are essential to the process' successful operation. Correspond directly to the protocols that control treatments in a randomized control trial.
 - ➤ *Input Metrics*: Describe a process' appropriate domain of application. Correspond directly to the eligibility criteria in a randomized control trial.
- 1) Consider what metrics related to medical outcomes, patient experience and cost are useful to understand what happened to the patient as they went through the process.
- 2) Consider what areas within the process are important to capture. Focus on key areas where decisions are made and where it may be useful to understand what decision was made and why. Consider areas of variation in practice. Will it be useful to track the details of the step in order to understand differences in practice that may exist (e.g. between physicians) to understand the impact that the various decisions have on the patient outcomes?
- 3) Consider what characteristics of the patient are important to know. What patient demographics, co-morbidities, or medical and surgical history is important to know as it drives treatment decision making and may impact patient outcomes?

Consider the role of the patient voice in identifying measures

Patient Reported Outcome Measures (PROMs) capture the patient perspectives on quality of life. PROMs are an umbrella term covering a range of survey tools used to obtain reports by patients on their health status, without interpretation by a clinician. Typically PROMs surveys are issued before, and at specific intervals following a health related procedure. Information gathered from the surveys may be indicative of whether or not healthcare interventions or services make a difference to patients' health and quality of life, *from their point of view*. PROMs information is typically collected via self-administered questionnaires on paper or computer, or in-person or telephone interviews, asking patients about symptoms, functionality, and various other aspects of physical, mental, and social health relevant to their quality of life.

Evidence shows that routine use of PROMs has the potential to influence health care. Not only can PROMs help patients and clinicians make better decisions, but can also enable comparisons of providers' performances to stimulate improvements in services and provide information to support evaluation of the efficacy, effectiveness and cost-effectiveness of health care treatments.

PROMs questionnaires may be generic or disease/condition specific. A general and widely accepted recommendation by experts is that generic and disease specific PROMs provide complimentary information.

Generic PROMS are designed to be used in any disease population. The EuroQol EQ-5D, SF Health Survey series and Health Utilities Index (HUI) are the most commonly used generic PROMs surveys. Generic survey tools enable comparisons to be made across different diseases and produce utility scores that can be used to calculate quality of life adjusted years (QALYS) for cost-effectiveness analysis.

Disease or condition-specific PROMs measure outcomes that are of importance for patients with a particular medical condition. They are more sensitive in detecting change over time and differences between groups of patients with the same condition. Condition-specific surveys provide more detailed information that is relevant to the practice of clinicians. An example of a disease specific survey tool currently used in Saskatchewan is the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) used to assess pain, stiffness, and physical function in patients with hip and/or knee osteoarthritis. For more information on common PROMS tools:

- EQ5D (<u>http://www.euroqol.org/</u>)
- SF-36 (http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html)

Consider how evaluation of Shared Decision-Making (SDM) and patient experience surveys can be utilized to capture the patient perspective of their journey.

- SDM measures (See the Tool #3: Shared Decision-Making: Patient Involvement in Treatment Decisions)
- Patient Experience Surveys

Consider metrics will be reported back to the group and how it will be used

- How will key metrics be presented (as proportions, raw numbers, etc.).
- How should the metrics be stratified? (Are there important patient characteristics that the metrics should be stratified by?)
- How often should the metrics be updated and shared? (Monthly, quarterly)?
- Who should the reports be shared with?

Consider what data will be needed to report these metrics

- Identify the data needed to report each metrics. Consider whether the data needed are available in existing datasets (consider data sources outlined in section 2b). Experience with other similar projects (e.g. VAWG) highlighted a lack of clinically detailed data within the existing Saskatchewan data sources. The data needed to track patient outcomes and processes may not be available and new data may be needed.
- Consider capturing new data and creating new databases to report the key metrics.

If creating new data, consider how new data should be collected

- **Identify where in the workflow the data needed is generated.** Add detail to the process map about where in the patient process key the information (the data) is captured.
- Consider how that information could be collected at the point-of-care. The most sustainable way to collect accurate data is to integrate the data collection process into workflow, collected by someone at point-of-care. Most often, the data needed to generate the metrics is information that is already collected by a clinician throughout the course of treating a patient. Use data for patient (disease management) but also for rolling up for reporting and accountability at the level of individual health professionals, facilities/clinics/practice groups, hospitals, regions and at the provincial and national level. It is important that the right data is collected once, at the point of origin and then used for all applications.
- For example, a physician may collect patient's medical history and comorbidities in a consult note. This is information that is also needed for key

- metrics for this project. Consider standardizing the consult note so that it can still be used by the individual physician to treat the patient, but can also be used for data collection (e.g. modify an open-ended consult note to include standardized check boxes).
- Observe the clinical process, the patient flow, and flow of information. It is valuable to see the process as it happens. Often you may see that the process in reality is different from the process that was described when mapped. Seeing the process in person can help understand where best the information can be captured, integrated into the workflow and transmitted.
- Don't hesitate to start with paper-based data collection. It is likely that new forms will undergo multiple iterations before a final version that satisfies both clinical needs and data collection needs, and it is much easier to modify paper versions.
- It is important to avoid recreational data collection and asking people to collect data that is not needed. Do not collect data that is not needed for metrics, just for the sake of collecting data.

Consider how data will be analyzed and reported

- If able to use existing data consider how often the dataset will be extracted from its data source (monthly, quarterly, and semi-annually). Consider who and how it will be analyzed and how it will be shared with the project team (frequency, formatting, etc.).
- If creating new databases consider how the data will flow from the point-of-care to source that can enter it into a database and analyze it. Options include faxing paper documents, or using a secure file-transfer program (FTP). An FTP is an online program that allows multiple users to access a shared account to upload and download files.
- Similar to using existing data, consider how the new data will be analyzed, reported and shared. Will metrics be reported as graphs or tables? How often will they be shared? Who will the metrics be shared with?

Consider types of privacy documents are needed in order to access, analyze, and share this data.

Consider transitioning to an electronic system

• If new data collection is paper-based consider transitioning it to an electronic system over time. As the project is replicated and spread it may become unsustainable to continue with a paper-based version. Movement to an

electronic platform may facilitate ease of data collection, data entry, analysis and reporting.

Saskatchewan Administrative Databases

The following are datasets that can be accessed from the Health Quality Council (HQC). If an interested party requests access to HQC datasets they must follow the HQC requirements for using HQC data. For more information contact Tracey Sherin, Director, Analysis and research Partnerships, tsherin@hqc.sk.ca.

Dataset	Key Variables in Dataset
Person Health Registration	Health Services Number (encrypted)
System (PHRS)	Person year of birth
	• Sex
	Marital status
	Registered Indian status
	Dates of coverage – initiation and termination
	Reason for termination
	Status of health insurance coverage
	Regional Health Authority where person resides
	Current recipients of social assistance
Hospital Discharge Abstract	Health Services Number (encrypted)
Database (DAD)	Year and month of birth
	• Sex
	Residence
	Date of admission
	Date of discharge
	Discharge diagnosis (ICD-9 or ICD-10, all fields)
	Procedure codes (CCP or CCI, all fields)
	Accident code
	Case-mix group
	Resource intensity weight
	Mortality in hospital flag
	Hospital identification number
	Hospital category
Institutional Supportive	Health Services Number (encrypted)
Care System Dataset	Type of admission
	Date of admission
	Date of discharge
	Reason for discharge
	Regional Health Authority where resident resides
Physician Services Claims	Health Services Number (encrypted)
File: Medical Services	Residence
Branch (MSB)	Provider MSB number (encrypted)
	Physician specialty
	Referring physician

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Dataset	Key Variables in Dataset
	 Fee code approved Diagnostic code (ICD or MSB) associated with service Service code Date of service Number of services Type of service or major group code Location of service code Payment information
Saskatchewan Resident Geography	 Health Services Number (encrypted) Urban or rural area of residence (based on estimated driving time from the centroid of person's residential postal code to centre of closest city with population > 15,000) Income quintile Regional Health Authority where person resides
Resident Assessment Index Minimum Data Set (RAI- MDS)	Identification Information Health Services Number (encrypted) Unique registration identification Assessment reference date Treaty/band Marital status Facility number Province/territory of issue Responsibility for payment Reason for assessment Responsibility/legal guardian Advanced directives Demographic Information Admission Date Admitted from/level of care (at entry) Lived along (prior to entry) Residential history (5 years prior to entry) Education (highest completed) Language Mental health history Conditions related to developmental disability status Cognitive Patterns Comatose Memory Memory/Recall ability Cognitive skills for daily decision making Indicators of delirium periodic disordered

Dataset	Key Variables in Dataset
	Change in cognitive status
	Communication/Hearing Patterns
	Hearing
	Communication devices/techniques
	Modes of expression
	Making self-understood
	Speech clarity
	Ability to understand others
	Change in Communication/hearing
	Vision Patterns
	• Vision
	Visual limitations/difficulties
	Visual appliances
	Mood and Behaviour Patterns
	Indicators of depression, anxiety, sad mood
	Mood persistence
	Change in mood
	Behavioural symptoms
	Change in behavioural symptoms
	Psychosocial Well-Being
	Sense of initiative/involvement
	Unsettled relationships
	• Past roles
	Physical Functioning and Structural Problems
	Bed mobility
	• Transfer
	• Mobility
	• Dressing
	• Eating
	• Toilet use
	Personal hygiene
	Bathing The Control of the Con
	Test for Balance
	Functional limitation in range of motion Madaga (large stier)
	Modes of locomotion Modes of transfer
	Modes of transfer Tack segmentation
	Task segmentation ADI functional (robab notantial)
	ADL functional/rehab potentialChange in ADL function
	Change in ADL function
	Continence in Last 14 Days
	Bowel continence
	Bladder continence

Dataset	Key Variables in Dataset
	Bowel elimination pattern
	Appliances and programs
	Change in urinary continence
	Disease diagnoses
	Disease and infection diagnoses
	C
	Health Conditions
	Problem conditions
	Pain symptoms
	Pain site
	Accidents
	Stability of conditions
	Oral/nutritional status
	Oral problems
	Height and weight
	Weight change
	Nutritional problems
	Nutritional approaches
	Parenteral or enteral intake
	Oral/Dental Status
	Oral status and disease prevention
	Skin Condition
	• Ulcers
	Type of Ulcer
	History of resolved ulcers
	Other skin problems or lesions present
	• Skin treatments
	Foot problems and care
	Activity Pursuit Patterns
	• Time awake
	Average time involved in activities
	Preferred activity settings
	General activity preferences
	Prefers change in daily routine
	Medications
	Number of medications
	New medications Injustions
	Injections Days received the following medication
	Days received the following medication Service Transfer and Broad days as
	Special Treatments and Procedures
	Special treatments, procedures and programs Intervention programs for model helpovious aganitive
	Intervention programs for mood, behaviour, cognitive Lace L
	loss

Dataset	Key Variables in Dataset
	Devices and restraints
	Hospital stay(s)
	Emergency room(er) visit(s) in last 90 days
	Physician visits in the facility the last 14 days or since
	admission
	Physician orders
	Abnormal lab values
	Discharge Potential and Overall Status
	Discharge potential
	Overall change in care needs
	Assessment information
	Participation in assessment
Vital Statistics	Health Services Number (encrypted)
	Date of death
	Cause of death
Prescription Drug Plan	Drug information
ALLDIN file	Pharmacologic-therapeutic class of drug
	Drug identification number (DIN)
	Drug active ingredient number
	Generic and brand names
	Strength and dosage form
	Date dispensed
	Quantity dispensed
	Provided information
	Prescribed identification number
	Dispensing pharmacy number
	Cost information
	Unit cost of drug materials
	Dispensing fee and mark-up
	• Consumer share of total cost
	Government share of total costTotal cost
Droggintian Drug Plan	TT 1:1 0 ' NT 1 / (1)
Prescription Drug Plan	Health Services Number (encrypted)Drug identification number (DIN)
Historical Claims	Date of dispensing
	 Quantity of drug dispensed
	Quantity of drug dispensedDrug type (EDS, MSD)
	Drug class (Major, minor)
Home Care Dataset	Health Services Number (encrypted)
Tionic Care Dataset	 Date of admission
	Date of discharge
	Type of admission
	Reason for discharge

Dataset	Key Variables in Dataset
Dataset	Discharge arrangements
	 Discharge arrangements Discharge from hospital prior to initiation of home
	care
	Living arrangements before admission
	Type of residence before admission
	Senior housing
	Regional health authority
	Out of province flag
Resident Assessment Index	Identification Information
Home Care Dataset (RAI-	Health Services Number (encrypted)
HC)	Province/territory issuing health care number
iic,	Demographic Information
	• Sex
	Aboriginal identity
	Marital status
	Language
	Education (highest complete)
	Responsibility / advanced directives
	Responsibility for payment
	Referral items
	Data case opened / reopened
	Reason for referral
	Understanding goals of care
	Time since last hospital stay
	Where lived at time of referral
	Who lived with at referral
	Prior residential care facility placement
	Assessment Information
	Assessment reference date
	Reason for assessment
	Location of Assessment
	Location of assessment
	Facility admission date
	Cognitive patterns
	Memory recall ability
	Cognitive skills for daily decision making
	Indicators of delirium
	Communication/Hearing Patterns
	Hearing
	Making self-understood
	Ability to understand others
	Communication decline
	Vision Patterns

Dataset	Key Variables in Dataset
	• Vision
	Visual limitations/difficulties
	Visual decline
	Mood and Behaviour Patterns
	 Indicators of depression, anxiety, sad mood
	Mood decline
	Behavioural symptoms
	Change in behavioural symptoms
	Social Functioning
	Involvement
	Change in social activities
	• Isolation
	Informal Support Services
	Two key informal helpers (primary and secondary)_
	Caregiver status
	• Extend of informal help (hours of care, rounded)
	Physical Functioning
	• IADL
	 Meal preparation
	 Ordinary housework
	 Managing finances
	 Managing medication
	o Phone use
	 Shopping
	 Transportation
	• ADL
	 Mobility in bed
	o Transfer
	 Locomotion in home
	 Locomotion outside of home
	 Dressing upper body
	 Dressing lower body
	o Eating
	o Toilet use
	o Personal hygiene
	o Bathing
	ADL decline Primary modes of legementian
	Primary modes of locomotion Stair climbing
	Stair climbingStamina
	Functional potential Continuous in Last 7 Days
	Continence in Last 7 DaysBladder continence
	Diaduel continence

Dataset	Key Variables in Dataset
	Bladder devices
	Bowel continence
	Disease diagnoses
	Disease and infection diagnoses
	Health problems and preventive health
	measures
	• Preventive health services (past 2 years)
	 Problem conditions present on 2 or more days
	• Pain
	• Falls frequency
	Danger of fall
	Lifestyle (drinking/smoking)
	• Health status indicators
	Other status indicators
	Nutrition/hydration status
	• Weight
	• Consumption
	• Swallowing
	Oral/Dental Status
	 Oral status and disease prevention
	Skin Condition
	Skin problems
	• Ulcers (pressure/stasis)
	 Other skin problems requiring treatment
	• Prior pressure ulcer
	Wound/ulcer care
	Environmental assessment
	Home environment
	Living arrangement
	Service utilization
	• Formal care (minutes rounded to even 10 minutes)
	Special treatments therapies, programs
	 Management of equipment (in last 3 days)
	• Visits in last 90 days of since last assessment
	Treatment goals
	Overall change in care needs The last off
	• Trade offs
	Medications
	Number of medications
	Receipt of psychotropic medication
	Medical oversight Consuling a /a dh arranga with madications
	Compliance/adherence with medications List of all modifications
	• List of all medications

Dataset	Key Variables in Dataset	
	Assessment information	
	Participation in assessment	
Physician Characteristics	Medical Services Provider number (encrypted)	
	Flag indicating general practitioner versus specialist	
	Specialty	

Important Documents Regarding Data

1. Data Sharing Schedule.

A Data Sharing Schedule is a legal document between the data owner and the party wishing to use data for a certain purpose. It outlines the terms of agreement for use of the data (data specifics, security, reporting conditions, etc.).

2. Patient Consent

If the project requires creating new databases and collecting new data, patient consent may be required. In most cases, because the data required is standard clinical information collected to treat the patient, consent is needed, not to collect the patient information, but rather to have the information used in another way (e.g. research, quality improvement). An example of a patient consent letter is provided on the following page.

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Dear Patient;

As described in the attached brochure, your surgeon is partnering with the Health Quality Council (HQC) of Saskatchewan, a quality improvement organization that works closely with the health system, to better understand and improve the care available to patients in Saskatchewan. The vascular surgeon you are about to see is seeking to collect information on the course of your care. This is routine medical information that your surgeon already collects to assist with your care. Your surgeon has authorized specific personnel at the HQC to provide reports about the health services they provide and with your consent, your medical information will be shared, via secure transfer, with those **specific personnel** from the HQC. Your information will be shared and used in accordance with the requirements of the *Health Information Protection Act*.

In addition to your demographic information, diagnosis, medical history and the dates and types of service provided to you, the surgeons would like to collect the following information:

- EQ5D Survey A quality of life survey to tell the surgeon about how your condition affects your daily life
- Patient Satisfaction Survey- For you to tell the surgeon about your experience with receiving care

Right now, you are asked to complete the *EQ5D survey*. You will be contacted on two occasions by phone and/or email by the personnel from the HQC that have been authorized to access your information, initially three months and then one year after the treatment you receive. In order to follow-up with you, the designated personnel from the HQC will require your contact information (name and phone number or email). The person (s) from the HQC who contacts you is authorized for this role by your surgeon and will be specifically trained to maintain your confidentiality. This survey information will help your surgeon follow up on your recovery as well as enable evaluation of the vascular surgical services available in Saskatchewan.

All information collected about you and your medical condition will be stored in your surgeon's office like the rest of your medical record. Additionally, information provided to HQC will be stored in a secure manner at the HQC. Only your surgeon, their office staff, and those specific individuals from the HQC will be allowed to access any information that directly identifies you. As part of the evaluation of vascular surgical services, the information collected from you may be linked to other health information about you (for example, prescription medications used; hospitalizations) that are collected by the Ministry of Health. This data linkage is done in a manner that protects your privacy by ensuring the information remains de-identified to all except your surgeon and his/her authorized health information service providers.

The information you provide will be kept secure and confidential. Your participation is voluntary. If you decline to participate your care will not be compromised in any way. You may withdraw your consent at any time. However, this withdrawal is not retroactive. If you have any questions please call the number on the brochure, or speak to your surgeon about why this project is important to them.

	I understand the information in this letter, and give my consent to the collection and use of information about me for the purposes of monitoring, evaluating and improving care provided by vascular surgeons.		
0	I prefer follow-up contact to be by: Phone; Phone #:	☐ Email; Email Address:	
	Name: (please print)		
	Signature:	Date (yyyy-mm-dd):	

Surgical Variation and Appropriateness Working Group (Vascular Working Group)

1. Use of administrative data to identify problem

In 2012, the Saskatchewan Discharge Abstract Database (administrative database) was queried and age-standardized rates of 30 high volume surgical procedures were reported. The rates were stratified based on patient's health region of residence, not where the procedure occurred. A committee of health system administrators, policy consultants, and physician leaders reviewed the report and noted substantial variation in rates of procedure between health regions for some procedures. A Variation and Appropriateness Working Group (VAWG) Physician Group was developed for four clinical areas with variation. One of these groups included vascular surgeons from Saskatoon Health Region and Regina Qu'Appelle Health Region to explore perceived variation between rates of infrainguinal bypass surgery.

2. Use of administrative data to further understand issue

To understand the root cause of the variation further queries were attempted with administrative databases to get more clinically detailed data. It was identified that the clinically detailed data needed was not available within existing data sets.

3. Processed map to identify key issues and metrics

The vascular surgeons recognized the importance of having this data to better understand patient outcomes and variation in patient populations and treatment process and supported the idea of developing a new data set. The group convened in March 2013 for a full day session. The patient process was mapped (from initial visit with the vascular surgeon through to the decision for medical treatment to follow-up). Variation in physician practice was noted on the process map as a key area to track.

After mapping the process they identified key outcome, process, and input metrics that would be important to capture to further understand patient outcomes. Examples of the key metrics identified include:

Outcome Metrics: % of patients that experience a complication following an invasive treatment

Process Metrics: By type, the % of patients that receive diagnostic imaging following a consult.

Input Metrics: % of patients seen by a vascular surgeon for consult, by Rutherford classification (disease severity)

5. Considered the data needed to report metrics

The data needed to report each metric was identified. For example, for the process metric, % of patients that receive diagnosis imaging following a consult the numerator and the denominator for the calculation were identified.

6. Considered how data will be collected

All of the data required to report these metrics is information that is routinely collected throughout the course of providing care to the patient. It is the information that a physician needs to make treatment decisions (with the exception of Patient Reported Outcomes). Four key areas where physicians collect patient information were identified, and new information sheets that were organized in a standard way to collect data were created. These included:

- 1. Patient information sheet collected after the initial patient consult with the surgeon. This information sheet captures key patient comorbidities, medical history and next steps regarding treatment.
- 2. Procedure sheet that captures information about the patient's treatment.
- 3. Discharge sheet that captures information about the patient's post-procedure experience.
- 4. Follow-up information sheet that captures information about the patient's post-hospital experience and follow-up.

Additionally, a PROMs information sheet was implemented to capture patient's completed pre-treatment and post-treatment (3 months and 1 year) which reflects the patient's perspective of quality of life.

7. Consider how data will be transferred

A paper based data collection began with using the information sheets in the physician's offices and in the hospital. A flow process for the papers to move from the hospital, to the physician's office for collation, to the Health Quality Council for data entry and analysis was developed. This process involved hospital and office staff.

8. Considered how metrics would be reported back

Individual physician reports were developed to share with each vascular surgeon within the project team. The reports provided their individual data, Saskatoon Health Region and Regina Qu'Appelle Health Region data, and provincial data. These reports included tables and graphs to report the key metrics.

9. Transition to electronic data system

After 12 months using the paper based patient information forms to collect data, conversations with eHealth Saskatchewan were initiated to consider transitioning to an electronic system, which better integrates data collection into the physician's workflow.