



# Squeezing into the Glass Slipper: Ethical Review and Oversight for Cross- organizational Quality Improvement Projects in Saskatchewan

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# The Cast

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- The “would-be princess”:
  - Health Quality Council (HQC)
    - “Happily ever after” = Continually improving health care in Saskatchewan
- The prince’s courtiers:
  - U of S REB
  - Health Regions (Saskatoon; Regina Qu’Appelle)
- The glass slipper:
  - Legal/ethics oversight structures for use of health information (HIPA; Tri-Council Policy Statement)



# The Story: A QI Fairy Tale

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- Scene 1: 2005
  - Province-wide quality measurement of diabetes quality indicators – Report
  - Chronic Disease Management Collaborative
    - Quality improvement collaborative launched by HQC: to improve primary care for diabetes and coronary artery disease; involves nearly 30% of Family/General practices
- Scene 2: 2007
  - Enhance province-wide measurement of diabetes quality by including indicators from laboratory testing (e.g. glucose control – HbA1c)
  - Aim: to monitor quality status and improvement across Saskatchewan (“happily ever after”)



# The path to “happily ever after” ...

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- Cohort of Sask residents with diabetes identified from linked administrative health data
- Link in clinical data from other data sources where helpful/able (e.g., laboratory data)
- Measure quality of care indicators (processes and outcomes) for cohort
- Report results back to health care providers and public to spur and monitor improvement
- Repeat... “ever after” (or at least until better measurement systems are widely in place)

# To get to happily ever after, the glass slipper must fit...



## ■ HIPA

- Governs use of personal health information
  - central principle: use only with consent
- Permits use without express consent if:
  - For use by **QA** committee of trustee or group of trustees
  - For **research** – under certain conditions, including REB approval
- For data disclosure (sharing) - need legal agreements in place between parties



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- Data sharing agreement between SaskHealth and HQC stipulates submission of HQC study proposals to REB – for either review/approval or exemption – per judgment of REB
- Little “hard and fast” guidance in the Tri-Council Policy Statement for REB to differentiate research/QA
- Given the intent/purpose of HQC studies and that it is being done using secondary analysis of de-identified data with minimal risk, U of S usually exempted these kinds of HQC studies from review – as QA studies.



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- However – there are differing interpretations of the relevant law and guidelines within Saskatchewan
- Not surprising given:
  - the relative newness of HIPA
  - lack of specific reference in HIPA or TCPS to Quality Improvement work (vs. QA)
  - No explicit consideration in HIPA or TCPS of how to consider work by entities like HQC, which may involve multi/cross-organizational QI work
  - Lack of definitional clarity around key terms such as “de-identified data”, “identifiable data”, etc.



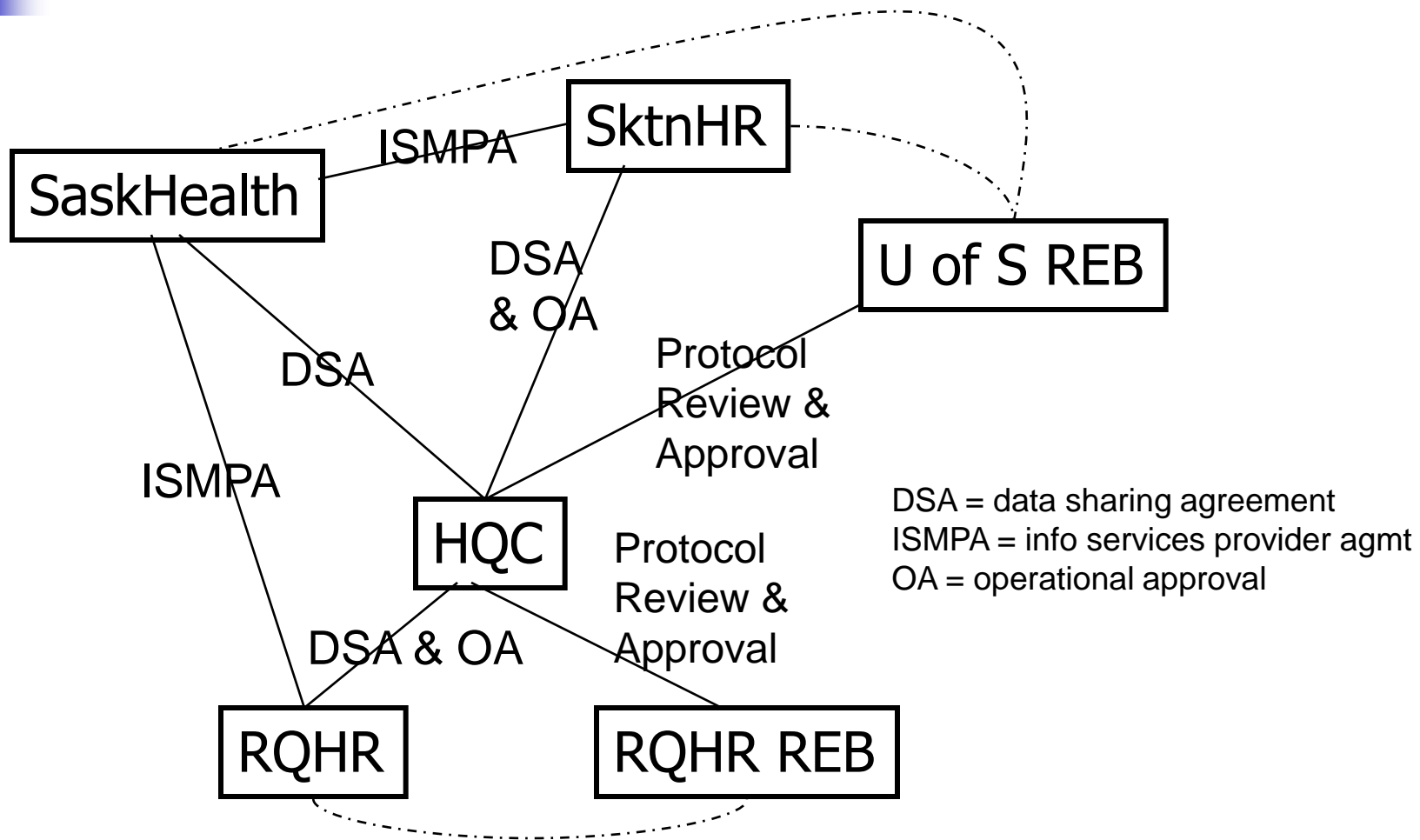
## Squeezing into the slipper

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Not having clarity cost everyone a lot of time and \$\$

- April 2007 - REB submissions (U of S & RQHR)
- May
  - U of S – exemption letter
  - RQHR REB approval certificate; Operational approval
  - Saskatoon HR - concerns re HIPA compliance of U of S REB exemption – operational approval on hold
- June through November
  - Many emails, phone calls, legal consultation fees to determine how the data sharing agreements should be worded and that, given current wording of HIPA, REB should review/approve, not exempt HQC studies
- December – data flows to HQC to enable start of study.

# Protecting people while increasing knowledge: squeezing into the slipper – the current solution





## Desired future: A slipper that fits

- More specific/consistent definitions for legal agreements of key terms about data (“de-identified”, “identifiable”, etc)
- Explicit reference in HIPA re conditions for disclosure/use of personal health info in multi-jurisdictional QI work, when involving HQC
- Well defined process for determining what fits under REB purview, and how to “protect people and increase knowledge” in circumstances not under REB purview.



Thank you