

**SEARCH**

C A N A D A

*Knowledge Unbound*



**ARECCI**

Calgary

5 May 2008

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**Protecting People while Increasing Knowledge:  
Ethics in Health Research, Evaluation  
and Quality Improvement**

**Ann Casebeer – Sarah Hayward - Sharon Matthias  
On behalf of the SEARCH Canada Team**

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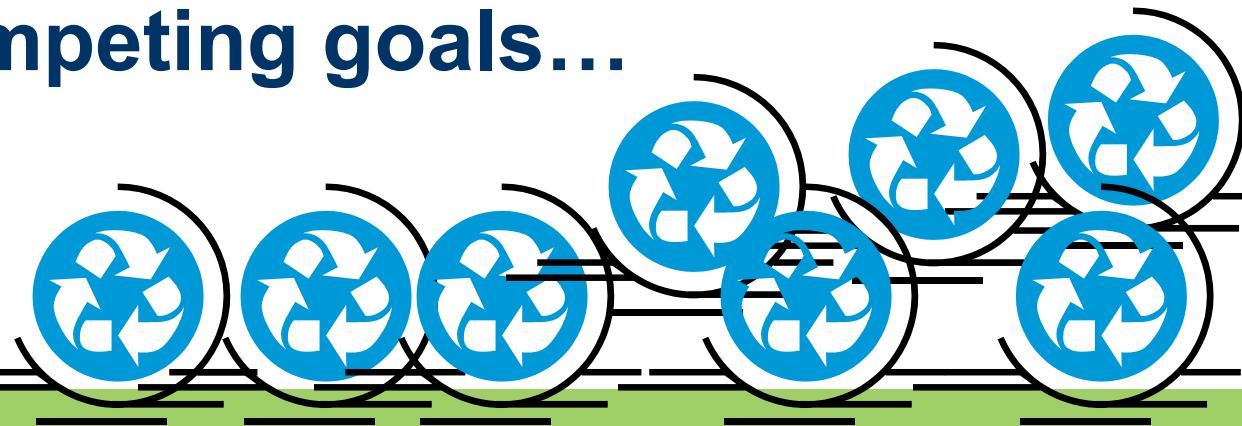
**5 May 2008**

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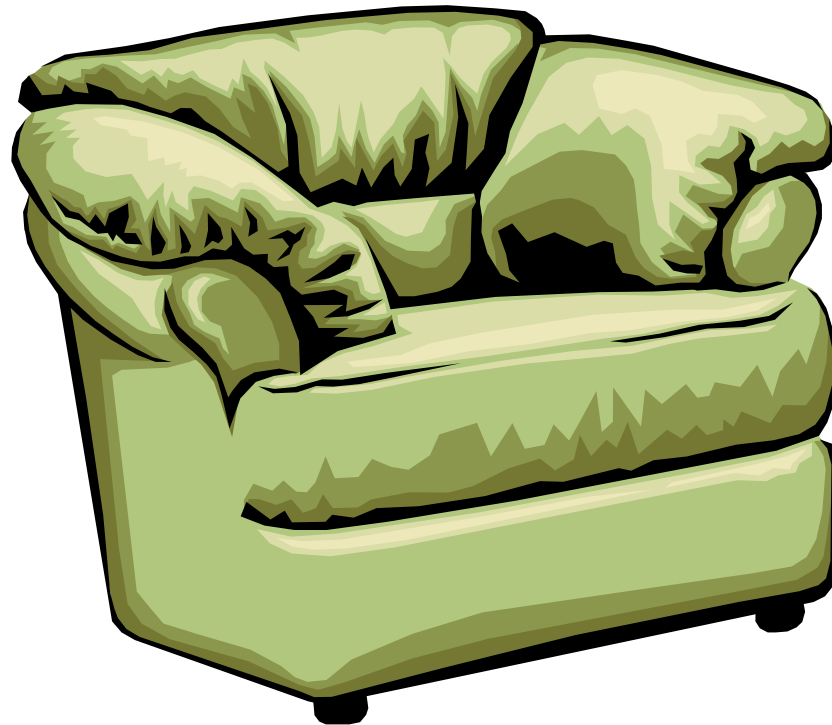
**Challenges to Concepts, Practices and  
Processes in the Ethical Management  
of Practice-based Research:  
The SEARCH Experience**

# First ...A Few Caveats...

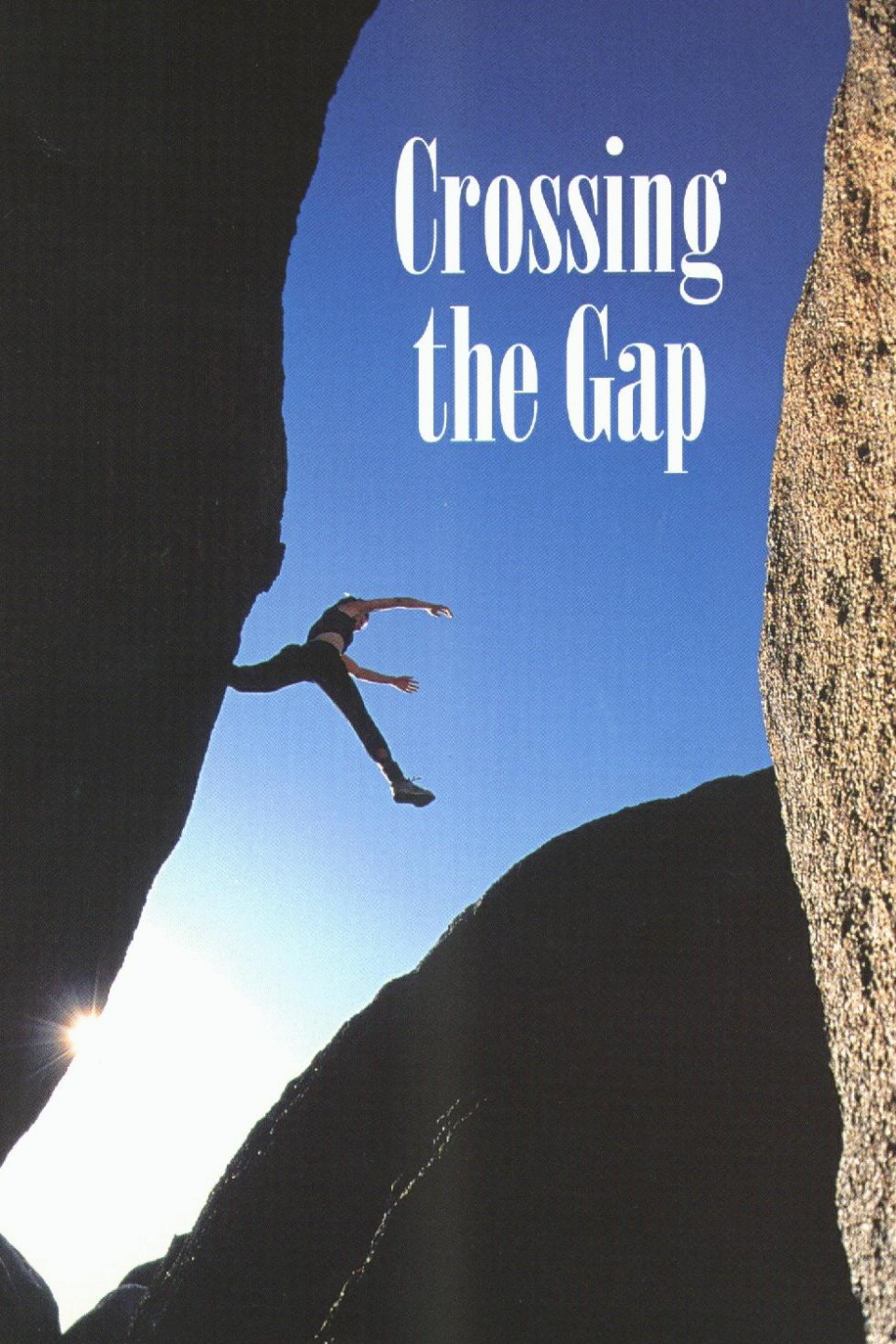
- **Ethical decision-making is almost always about balancing the potential to do good – or at least better – against the possibility of doing bad – or even just less well**
- **Ethical dilemmas abound because there are almost always multiple perspectives and often competing goals...**



“Where you sit is where you stand”



Robert Miles - Philosopher

A person is captured in mid-air, jumping across a significant gap between two dark, silhouetted rock formations. The background is a clear, bright blue sky, with a sun flare visible in the lower-left corner. The overall scene conveys a sense of challenge and achievement.

# Crossing the Gap

**“Getting knowledge is only halfway there. The final challenge is to use it, to close the gap between what we know and what we do, so our health care is based on research evidence about what works best.”**

**AHFMR Annual Report 1996**

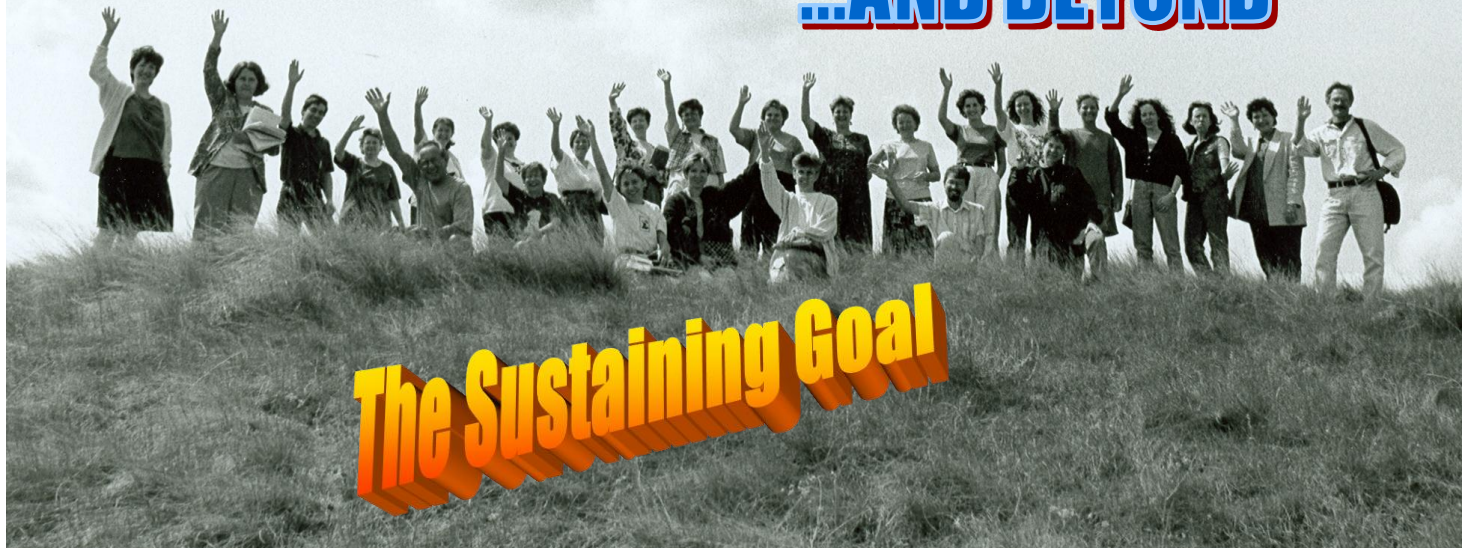
# SEARCH Canada

- **A not-for-profit dedicated to creating a culture of knowledge within the health system**
- **Helping organizations make the best decisions through the development of people, relationships and information**
- **Capacity building via development of COPs and sustained networks**

# SEARCH Canada

.....directed to the discovery of new knowledge and the application of that knowledge to improve health and the quality of health services in Alberta....

**...AND BEYOND**



**The Sustaining Goal**

# ETHICAL

## CONCEPTS-PRACTICES-PROCESSES



# Context

- **Great strides have been made...**
- **Practitioners are active participants in choosing using and creating new knowledge...**
- **The importance of ethical conduct and ethical review is recognized...**
- **There is substantial goodwill and increasing opportunity to support ethical practices...**

# Partners and Alliances Abound

- **SEARCH Canada**
- **CREBA**
- **ARECCI**
- **Tri Council Agreements**
- **Reciprocal Recognitions**
- **?**
- **?**

# Challenges Continue

- **A 25 year old women suffers from irreversible paralysis from the neck down caused by a neurological disorder. She is dependent upon a respirator to keep her alive. She has been in the hospital for more than two years and thoroughly understands her medical condition and prognosis.**

» Baylis et al, Ethics in Canada, 1995

# Dilemmas Remain



- **She asks her physician to disconnect the respirator.**
- **What should the physician do?**

# Challenges Extend to New Domains

- **An important policy level decision needs to be taken by the Regional Board next month. Practitioners have been working to identify existing evidence that may be relevant to this decision. What they have found is judged in practice to be important and relevant...If reviewed for reliability and validity – the quality of the evidence is ‘poor’...**



# Dilemmas Remain

- **Is there an ethical obligation to improve the quality of the evidence?**
- **Is it in fact justifiable in terms of harm versus good if access to ‘better’ evidence is delayed so much by time for new research and review that the policy decision moment is lost?**
- **What should the Regional Board do?**

# Challenges Extend to New Domains

- **A manager (a SEARCH participant?) has taken up the challenge of asking the question before acting: “what is the evidence?”** (Received Wisdom: CHSRF, 2007) **and believes that ‘knowing something as a researcher implies an obligation to act as a manager’. The ‘evidence’ is at odds with current regional practice...**



# Dilemmas Remain

- **Is there a dilemma inherent in the dual role of manager and practitioner?**
- **What should ‘scholar Practitioners’ do?**

# Challenges Extend to New Domains

- **Four Practitioners from four RHAs are participating in a provincial project as part of a recognized learning opportunity. They are supported by their learning partner, their regional managers, their academically based faculty mentors. They have sought and eventually received all ethical and scientific and managerial approvals.**



# Dilemmas Remain

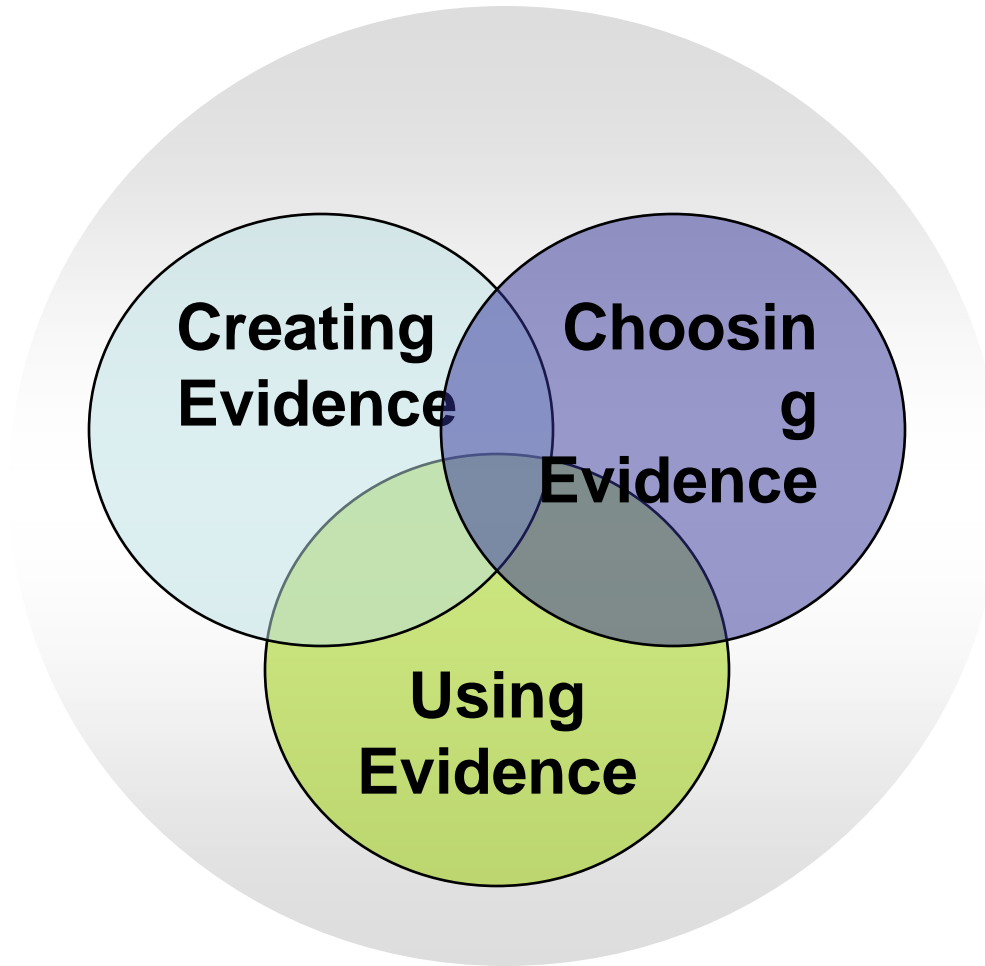
- The ‘lawyers’ review the evaluative research proposal for final sign off.
- What should they do?

# Opportunities Moving Forward

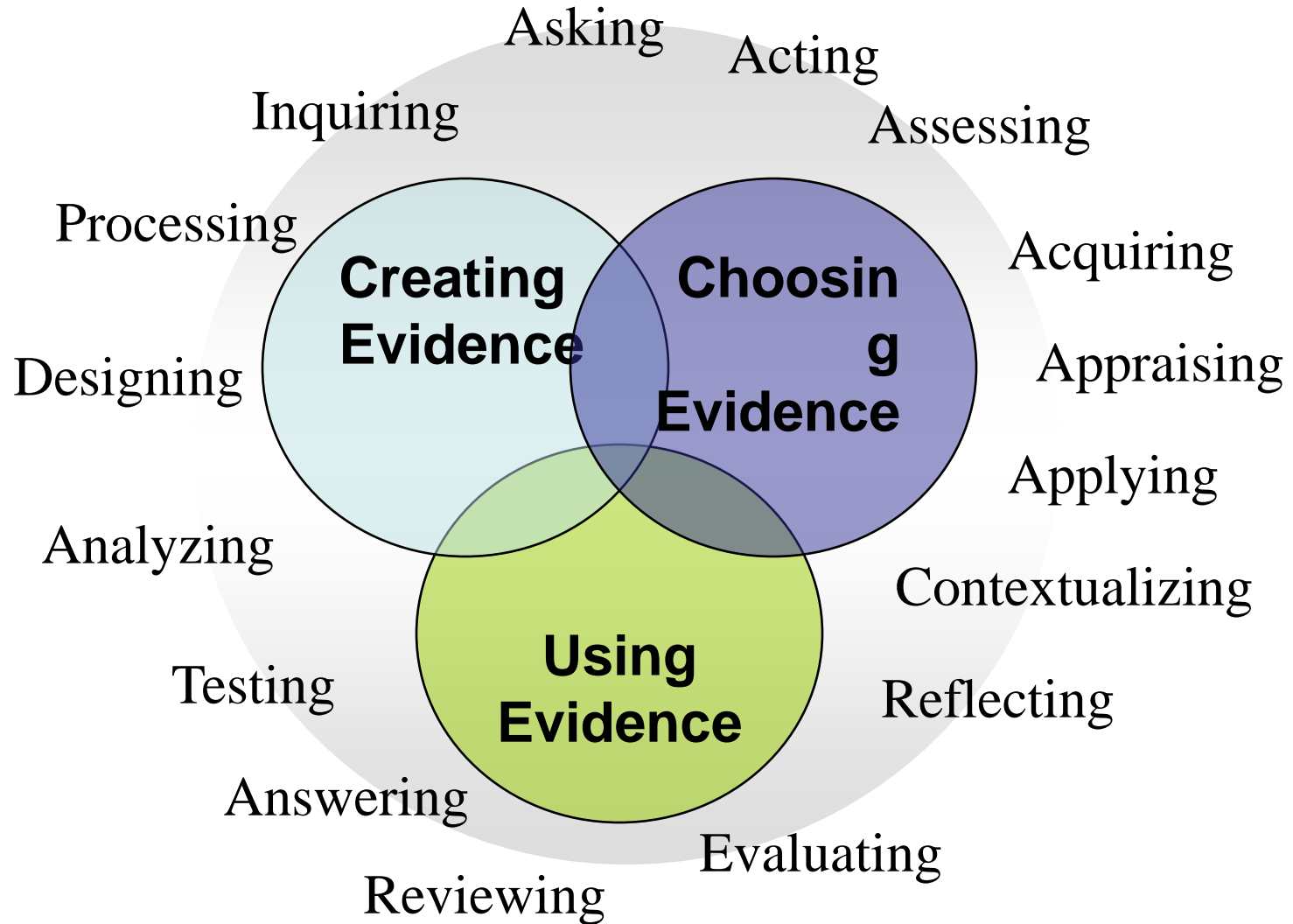
- **Promote a ‘just and trusting’ culture for ethical conduct and oversight (*and when appropriate*) ethical review of -**
  - health research
  - evaluation
  - quality assurance
  - good practice

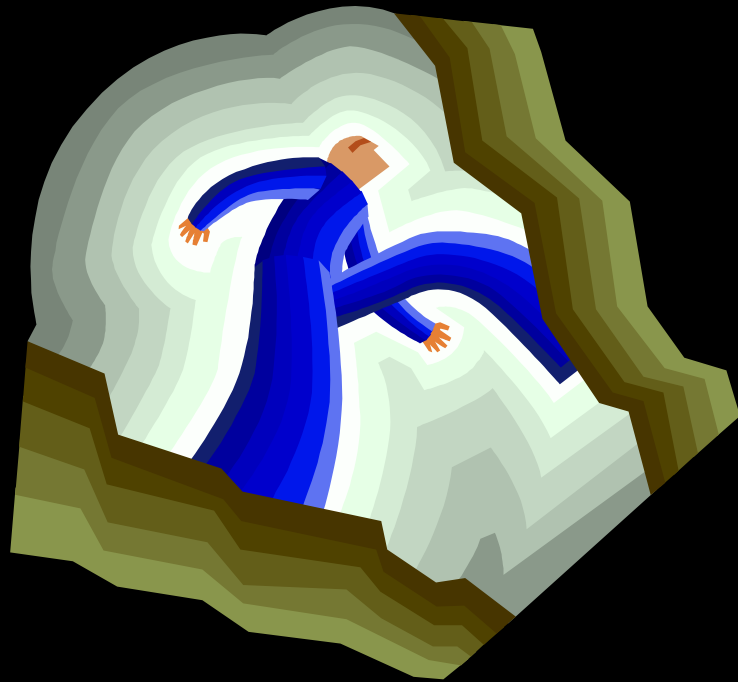
# Possibilities???

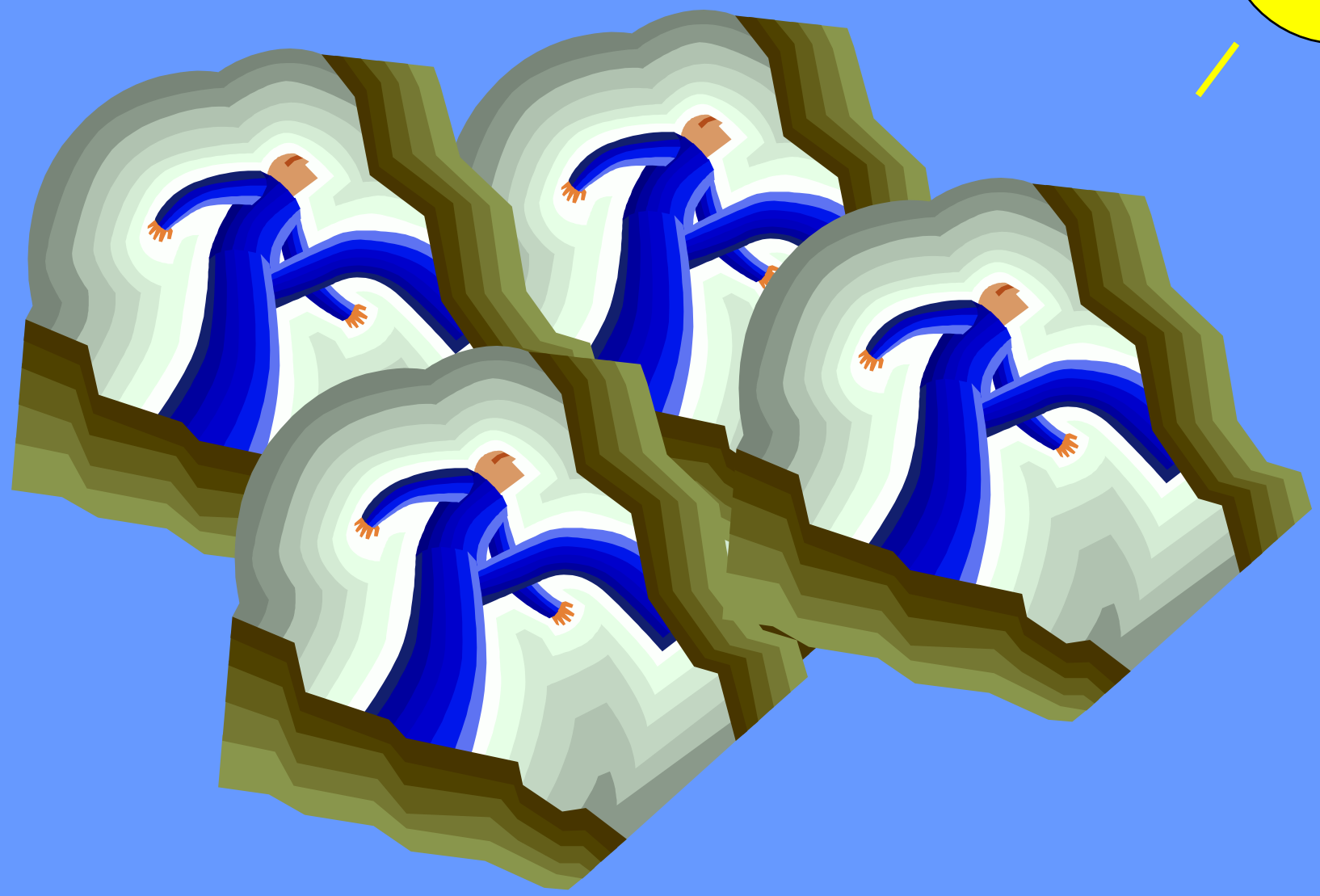
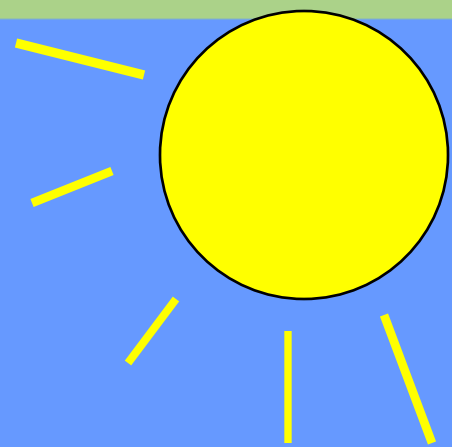
- **Common Protocols?**
- **Provincial Review (and Renewal?) processes?**
- **Tailored & enhanced peer review?**
- **Mentoring available for novices?**
- **‘learning’ counts on the benefits side of the equation?**
- **???**...



**In Context**







# Want to Connect?

Contact any of us with further thoughts  
and ideas:

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