

# Update on Quality Activities in Clinical Genetics

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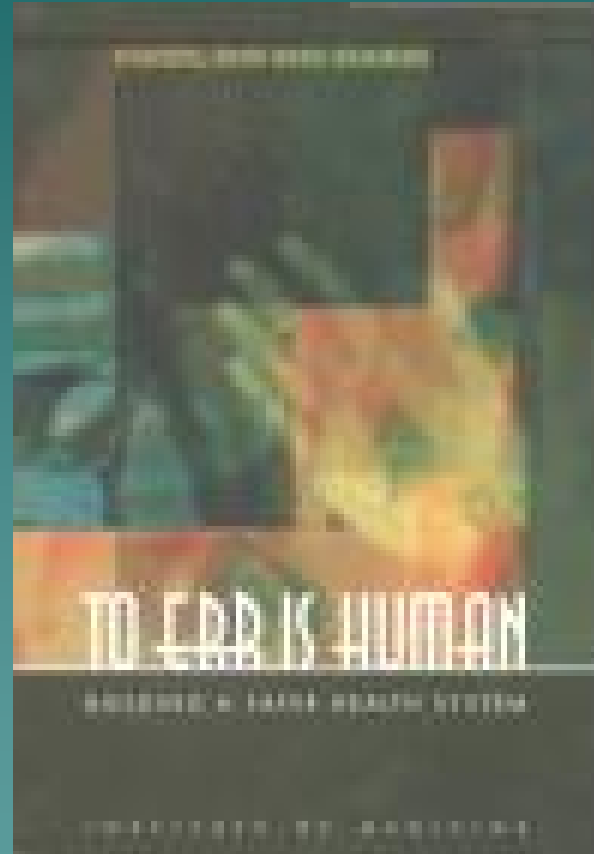




# Objectives

- ◆ Brief recap on quality improvement (QI)
- ◆ Discuss visibility of QI within clinical genetics
- ◆ Outline QI projects currently proceeding or in development
  - Introduction to MSGRCC/InheritQual project presentation

# November 30, 1999

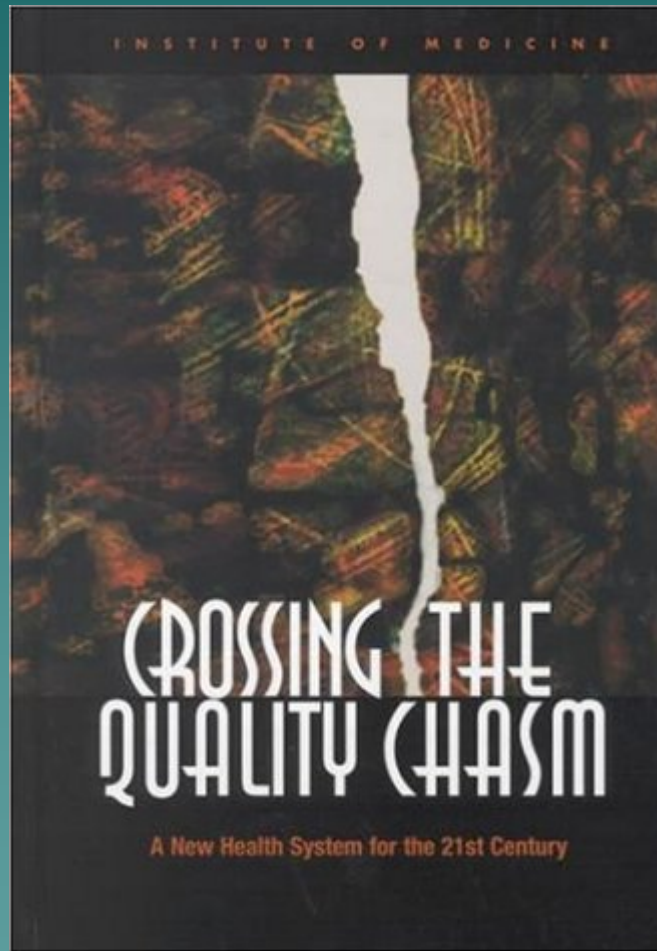




# To Err is Human Medical Injuries

- ◆ 44,000-98,000 deaths per year
- ◆ More people die from medical errors than from breast cancer or AIDS or motor vehicle accidents
  - Confirmed in Canadian and Utah/Colorado studies
- ◆ Direct health care costs \$9-15 billion/year
- ◆ It's a conservative estimate!!

# March 1, 2001



“Between the health care we have and the care we could have lies not just a gap, but a chasm.”





# How Good Are We?


- ◆ Only 50% of Americans receive recommended preventive care
- ◆ Patients with acute illness
  - 70% received recommended treatments
  - 30% received contraindicated treatments
- ◆ Patients with chronic illness
  - 60% received recommended treatments
  - 20% received contraindicated treatments

Schuster et al. How good is the quality of healthcare in the United States? *Milbank Quarterly* 76:517-63, 1998



# Quality Improvement is the Science of Process Management

Health care delivery is a system made up of  
thousands of interlinked processes





# Defining and Measuring Outcomes in Medicine

- ◆ Physical outcomes
  - Medical outcomes: complications and therapeutic goals
  - Patient outcomes
    - ◆ Functional status measures
    - ◆ Perceptions of medical outcome
- ◆ Service outcomes
  - Satisfaction: patients and families, referring providers, other 'customers'
  - Includes access
- ◆ Cost outcomes
  - Another outcome of the clinical process
  - Includes cost of burden of disease



# Medical Outcomes

- ◆ Appropriateness (referral and treatment indications)
- ◆ Complications (process failures)
- ◆ Therapeutic Goals
  - If goal not met, this is a process failure
- ◆ Functional status (as reported by the patient)



# Service Outcomes

- ◆ Clinician-patient relationship
  - Bedside manner
  - ‘caring and concerned’ clinician
- ◆ Access issues
  - Scheduling, travel, physical comfort, waiting
- ◆ Operate by a separate, general process that is independent of medical outcomes



# The Value Equation

$$\text{Value} = \begin{array}{l} \text{Medical Outcomes} \\ + \\ \text{Service Outcomes} \\ + \\ \text{Cost Outcomes} \end{array}$$

The goal is the best possible medical and service outcomes at the lowest necessary cost



# Quality Assurance

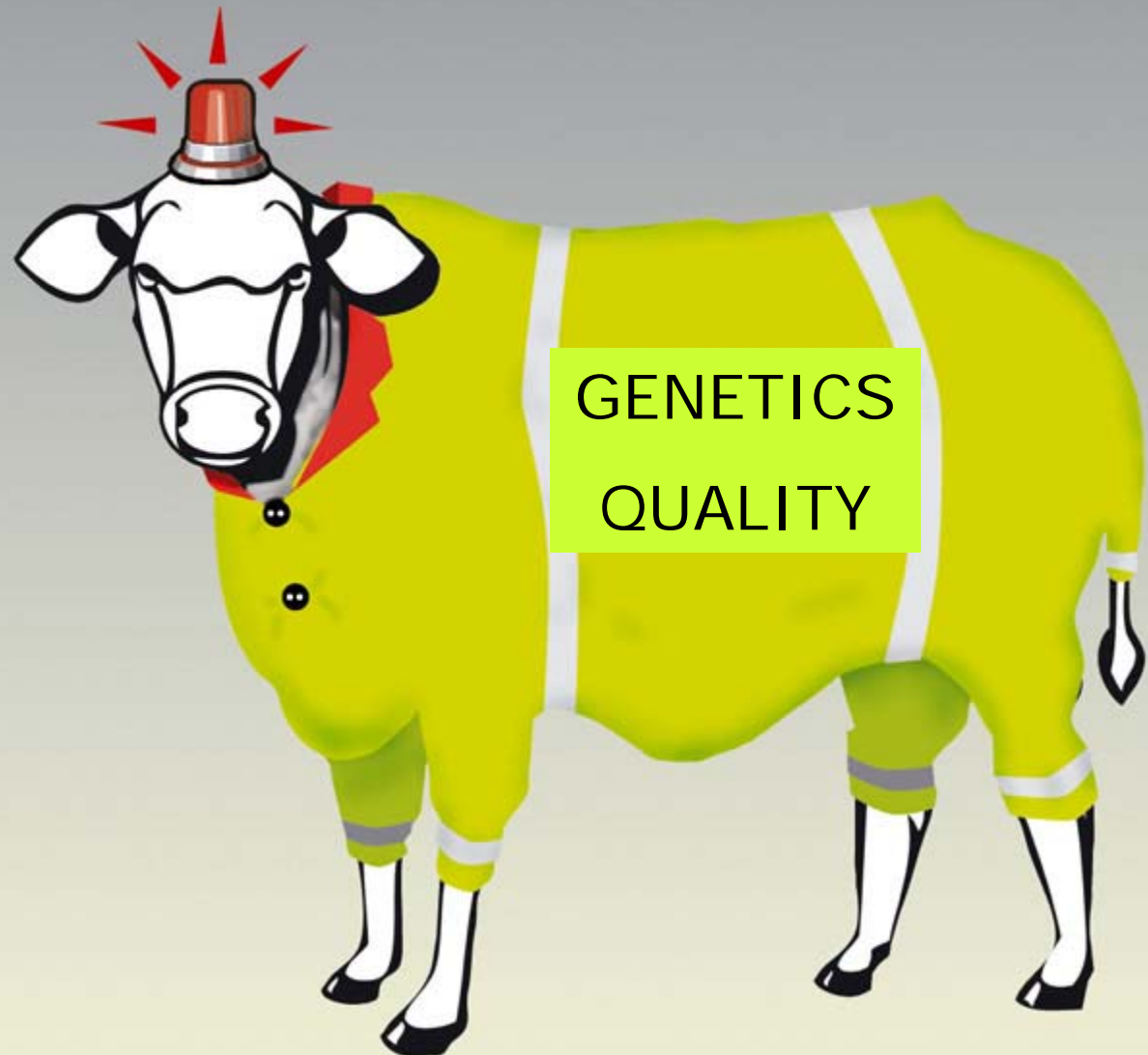
- ◆ Guidelines or standards developed (internally or externally) and goals set
  - Usually developed by experts without input from 'consumer' of service
- ◆ Measurements are for adherence to guideline/standard (compliance)
- ◆ Deficiencies identified
- ◆ Feedback provided
  - Frequently punitive




# Quality Assurance Insufficient

- ◆ Hospital QA programs mandated by Joint Commission since early 1990s
- ◆ No significant improvement in care seen
  - Reliance on education
- ◆ Many measures are trivial
- ◆ QA has a role, but will not result in substantial improvement without tools of process management and outcome measures

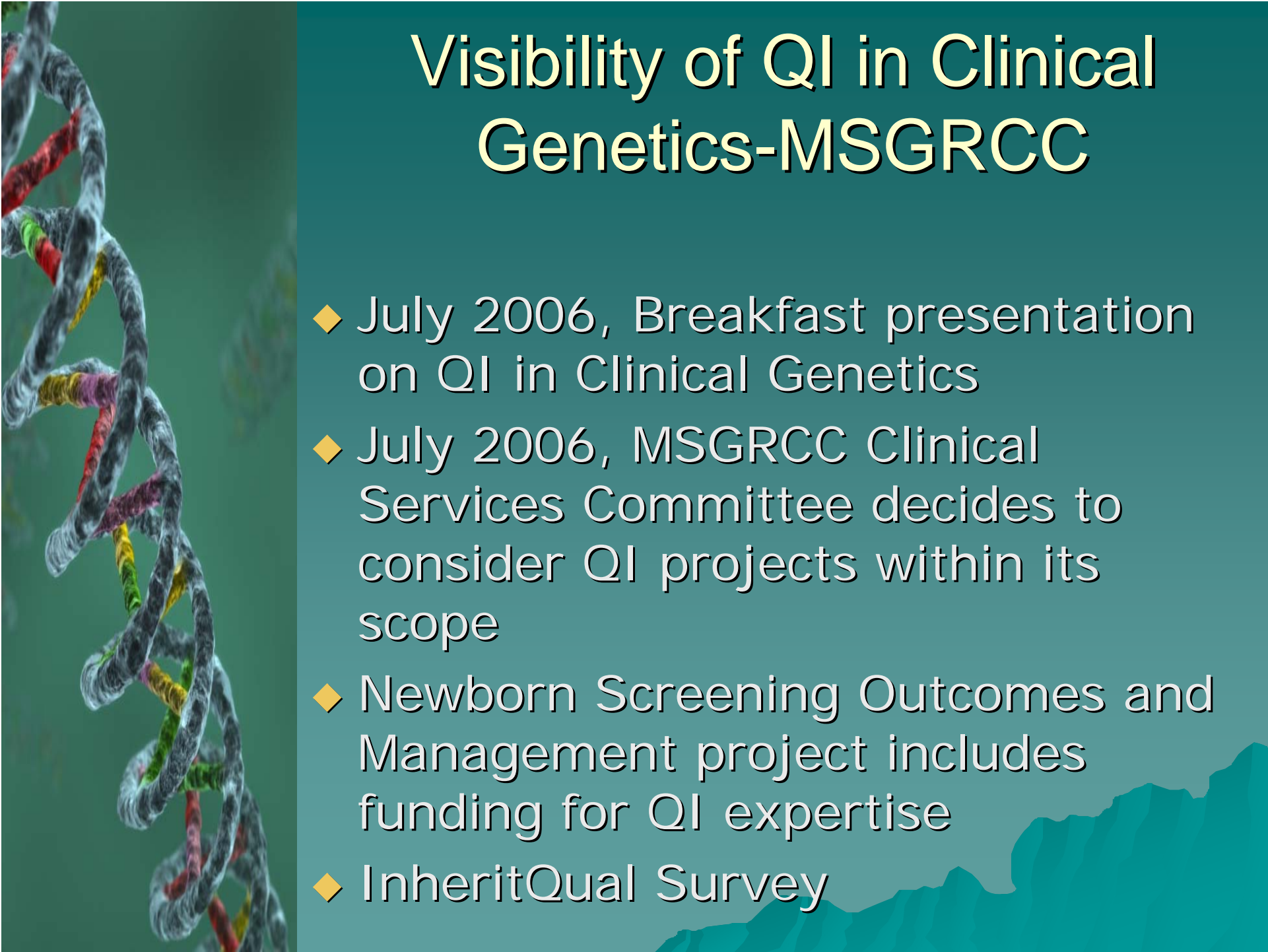
# Visibility of QI in Clinical Genetics






# Visibility of QI in Clinical Genetics-National

- ◆ March 2006 presentation at ACMG/MOD meeting on QI
- ◆ December 2006 First meeting of the Clinical Genetics Quality Special Interest Group (SLC)
- ◆ February 2007 NSGC expresses willingness to collaborate with ACMG QI initiatives that fit NSGC strategic goals
- ◆ March 2007 ACMG Board of Directors officially designates the Quality group as an official Special Interest group of the ACMG
- ◆ ABMG Expanded Maintenance of Certification requires “demonstration of participation in quality improvement activities”
- ◆ Interest and participation from Canadian members



# Visibility of QI in Clinical Genetics-MSGRCC

- ◆ July 2006, Breakfast presentation on QI in Clinical Genetics
- ◆ July 2006, MSGRCC Clinical Services Committee decides to consider QI projects within its scope
- ◆ Newborn Screening Outcomes and Management project includes funding for QI expertise
- ◆ InheritQual Survey



# QI in Clinical Genetics

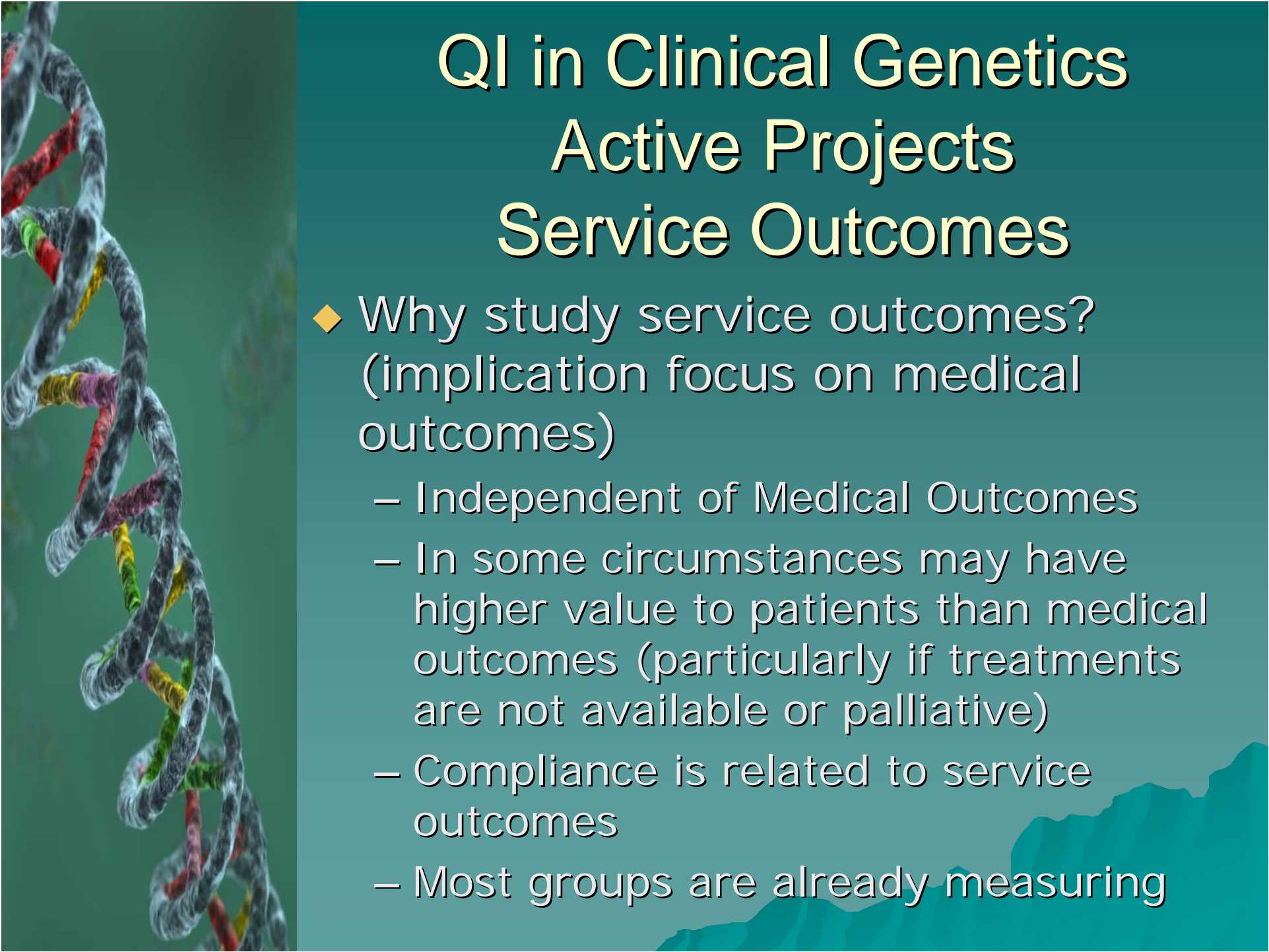
## Active Projects

### Medical Outcomes

- ◆ Cystic Fibrosis Foundation
- ◆ Standardized evaluation of children with DD/MR (NEG)
- ◆ ACMG PPG developing evidence-based review of genetic evaluation of autism
- ◆ Use of Family History by primary care physicians
- ◆ Quality improvement in inborn errors of metabolism (MSGRCC)
- ◆ NSGC define 'competent' pedigree

# Shared Baseline






# QI in Clinical Genetics

## Active Projects

### Service Outcomes

- ◆ Why study service outcomes?  
(implication focus on medical outcomes)
  - Independent of Medical Outcomes
  - In some circumstances may have higher value to patients than medical outcomes (particularly if treatments are not available or palliative)
  - Compliance is related to service outcomes
  - Most groups are already measuring




# QI in Clinical Genetics

## Active Projects

### Service Outcomes

- Patient satisfaction
  - ◆ Do we need a genetic-specific tool?
  - ◆ Do we need sub-tools (prenatal, cancer)?
  - ◆ Create a validated reliable tool(s)
  - ◆ Use tool to
    - Establish a baseline
    - Understand components of patient satisfaction with genetic encounter
    - Use to inform future encounters
    - Explore how satisfaction relates to information transfer

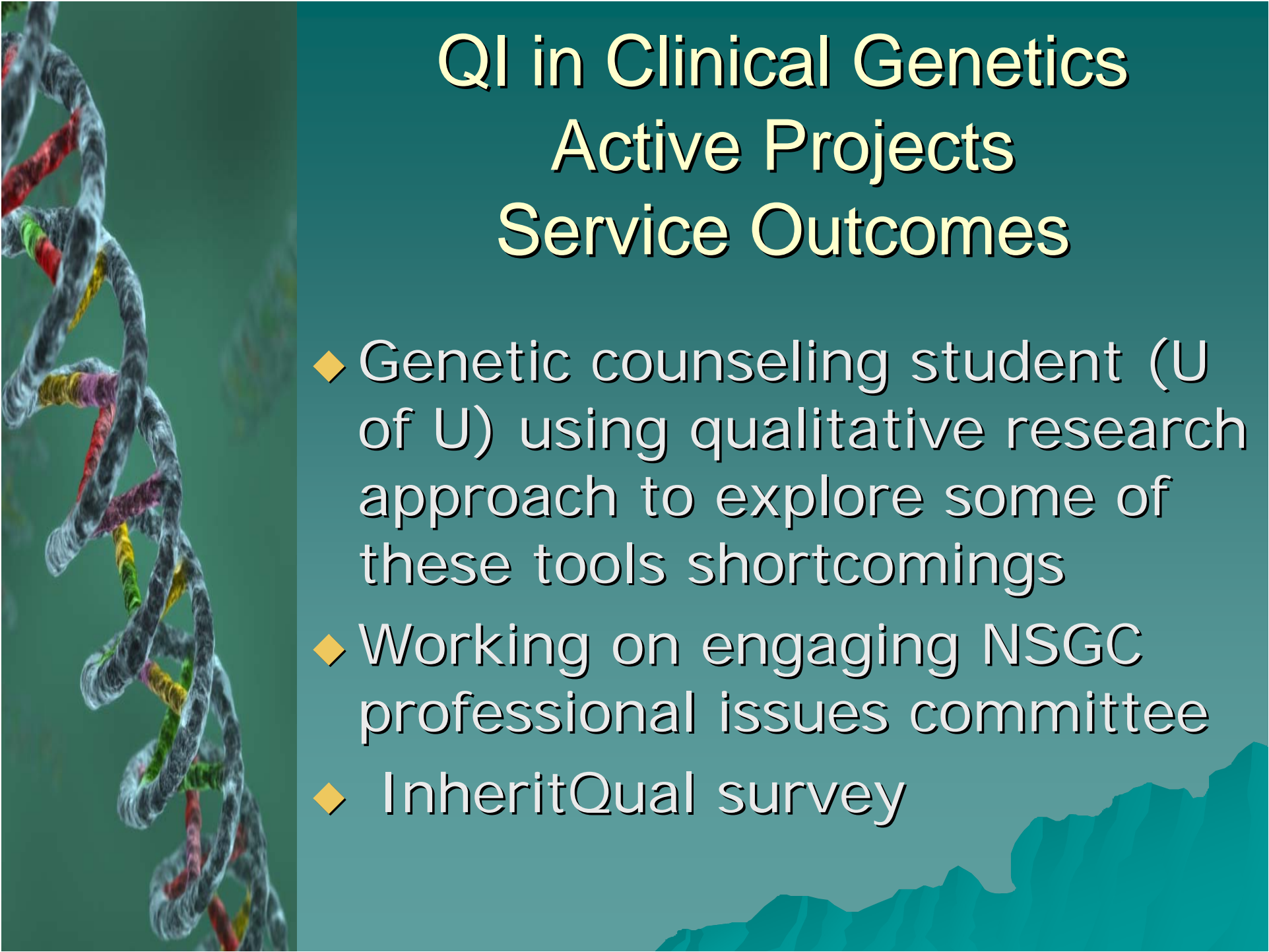


# QI in Clinical Genetics

## Active Projects

## Service Outcomes

- ◆ Review literature for patient satisfaction tools that have been tested for reliability and validity in genetic settings
  - A few such tools have been published
  - Tools perform differently outside of setting developed



# QI in Clinical Genetics

## Active Projects

### Service Outcomes

- ◆ Genetic counseling student (U of U) using qualitative research approach to explore some of these tools shortcomings
- ◆ Working on engaging NSGC professional issues committee
- ◆ InheritQual survey