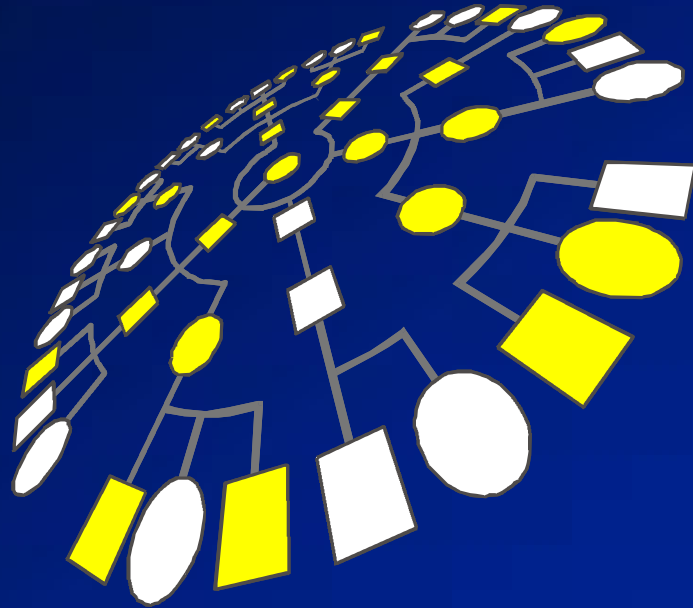


# Life Knowledge Park Symposium

## Eastern Promise



*Judy WC Ho*  
*Hereditary Gastrointestinal Cancer Registry*  
*Hong Kong*

# Hereditary Colorectal Cancer Syndromes in Chinese

- Social, cultural & psychological barriers among Chinese may aggregate the burden of a hereditary colorectal cancer family in Hong Kong

# Cultural & Social Barrier

## Parent-child relationship

- Authoritarian approach
- Not emotionally expressive
- Social reality: single working parent

Lack of communication & close  
relationship

# Cultural Barrier

## Attitude to hereditary disease

- A family curse
- Intense guilt of parent
  - Overprotection
  - Undue anxiety

# Social Barrier

## Social stigma & discrimination

- Regard cancer as infectious
- Lack of legal protection against social discrimination
- Regarding own hereditary condition as secretive
  - Social isolation

# Psychological Barrier

- Previous study on genetic testing for hereditary colorectal cancer (*Ho et al 2003*)
  - Those with higher perceived risk focused more on the harmful consequence of genetic testing
- Such barrier may affect surveillance compliance

# Reaching Out to Disaffected Teenager

## Preparatory work

- Initial contact by Registry staff before due for screening
- Clinician: develop rapport with teenager
  - Initial social contact through Registry activity

# Reaching Out to Disaffected Teenager

## Counseling & Education

- Setting: not in clinic
  - A less threatening environment
  - Allow sufficient time: > 1 session
  - Preferably during school holidays
- Speak in ways teenager can understand
  - Problem: insufficient educational material
- Use questions to check understanding
- Encourage teenager to ask questions

# Reaching Out to Disaffected Teenager

## Counseling strategy

- Understand family dynamics can facilitate the formulation of counseling strategy
- Absence of parent may help

# Reaching Out to Disaffected Teenager

## Endoscopic surveillance & prophylactic surgery

- Minimize unpleasant experience
- Performed by someone they know & trust
- Adequate psychological preparation
  - Experience sharing by other teenager with similar experience

# Reaching Out to Disaffected Teenager

## Social support

- Through Registry activities
  - Self-help group meeting
  - Workshop
  - Volunteer program
- Support from fellow FAP families
  - Teen to teen; mum to mum

# Reaching Out to Disaffected Teenager

- Be patient
- It takes time
- The reward is worth the effort