

# **Experience Enhancement from Oversea Observership in Paediatric Palliative Care in Canada**

**Oversea Corporate Scholarship Program  
for**

**Hong Kong Children's Hospital 2015/16**

**Paediatric Palliative Care**

**The Hospital of Sick Children, Toronto**

**2 Nov 2015 – 20 Nov 2015**

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**SickKids®**

- **Children Hospital**
- **Located at Toronto, Canada**

The logo for SickKids, featuring the word "SickKids" in a bold, blue, sans-serif font. The "i" in "Kids" has a small registered trademark symbol (®) above it.

- No palliative ward
- No designated palliative bed
- Paediatric Advanced Care Team (PACT) provide consultative palliative care service
- Primary care team are looking at extending life, prolonging life, finding cures; PACT works with other teams and family to **maximize comfort** and **promote Quality of Life.**

## Goals of Care

- Help to plan for the future so that difficult decisions are not made during a crisis
- Work with family to make the best possible decisions and emphasis on Quality of Life

## Communication & Decision Making

- Discuss with family about worried matters, clarify misconceptions
- Help siblings cope with the changing situation and the worries

## What PACT do

## Management of Pain and Other Symptoms

## End of Life Care

e.g. create meaningful legacies/memories

# PACT Members in SickKids



# Role of PACT Members

## Palliative Care Physician

- offers insight into the symptoms management
- guides the team in understanding the medical aspects of the child's condition
- designs and performs education on paediatric palliative care

## Clinical Nurse Specialist / Nurse Practitioner

- works expertly and closely with the multidisciplinary team to achieve realistic healthcare goals for the child and the family
- manages symptoms and provides care to the entire family
- designs and performs education on paediatric palliative care

## Grief Support Coordinator

- provides clinical counseling to families and patients
- helps the dying patients and their families prepare for the end by making the memorial arrangements
- provides psychological support to staff

## Group 1

- Potentially curable conditions
- Palliative care may be needed in addition to curative, or if it fails

Examples:

Advanced or progressive cancer or cancer with a poor prognosis;  
Irreversible organ failure;  
Trauma or sudden severe illness;  
Extreme prematurity

## Group 2

- Conditions that may need long periods of intensive treatment but inevitably lead to early death

Examples:

Cystic fibrosis  
Duchenne muscular dystrophy

## Paediatric Palliative Patient Categories

## Group 3

- Progressive fatal condition without curative treatment options
- No cure is possible and care is palliative from the time of diagnosis.

Examples:

chromosomal diseases such as Trisomy 13 & 18;  
rare metabolic diseases e.g. Mucopolysaccharidoses

## Group 4

- Irreversible but non-progressive irreversible conditions
- Leading to complications and premature death

Examples:

Severe cerebral palsy;  
Brain or spinal cord injuries due to trauma or infection;  
Severe brain malformations e.g. anencephaly

# PACT

- A referral is made by primary team physician with parents consent
- PACT conduct daily inpatient clinical rounds, complex case conference & multi-disciplinary meeting



# Consultative Services

- Initial consultation
- Follow up
- Family meeting/ Counseling
- Case conference
- Bereavement support
- Others

# Initial Consultation

- Meet with in-patient's family at bedside or Family Room, talk with family about
  - ✧ What are you hoping for?
  - ✧ What do you worry about?

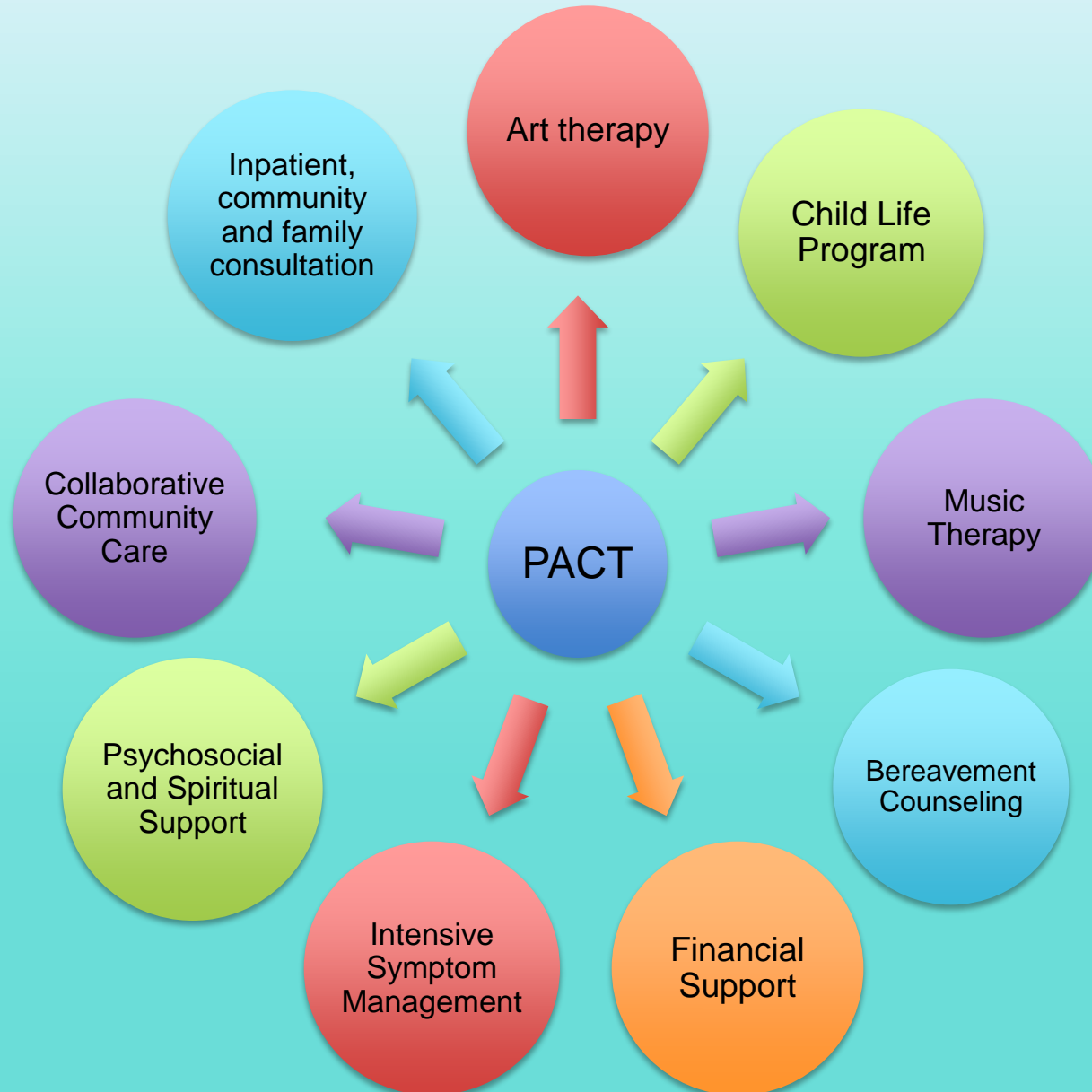
then translate into actions that can take & find something that can do to make a little bit better



# Documentation

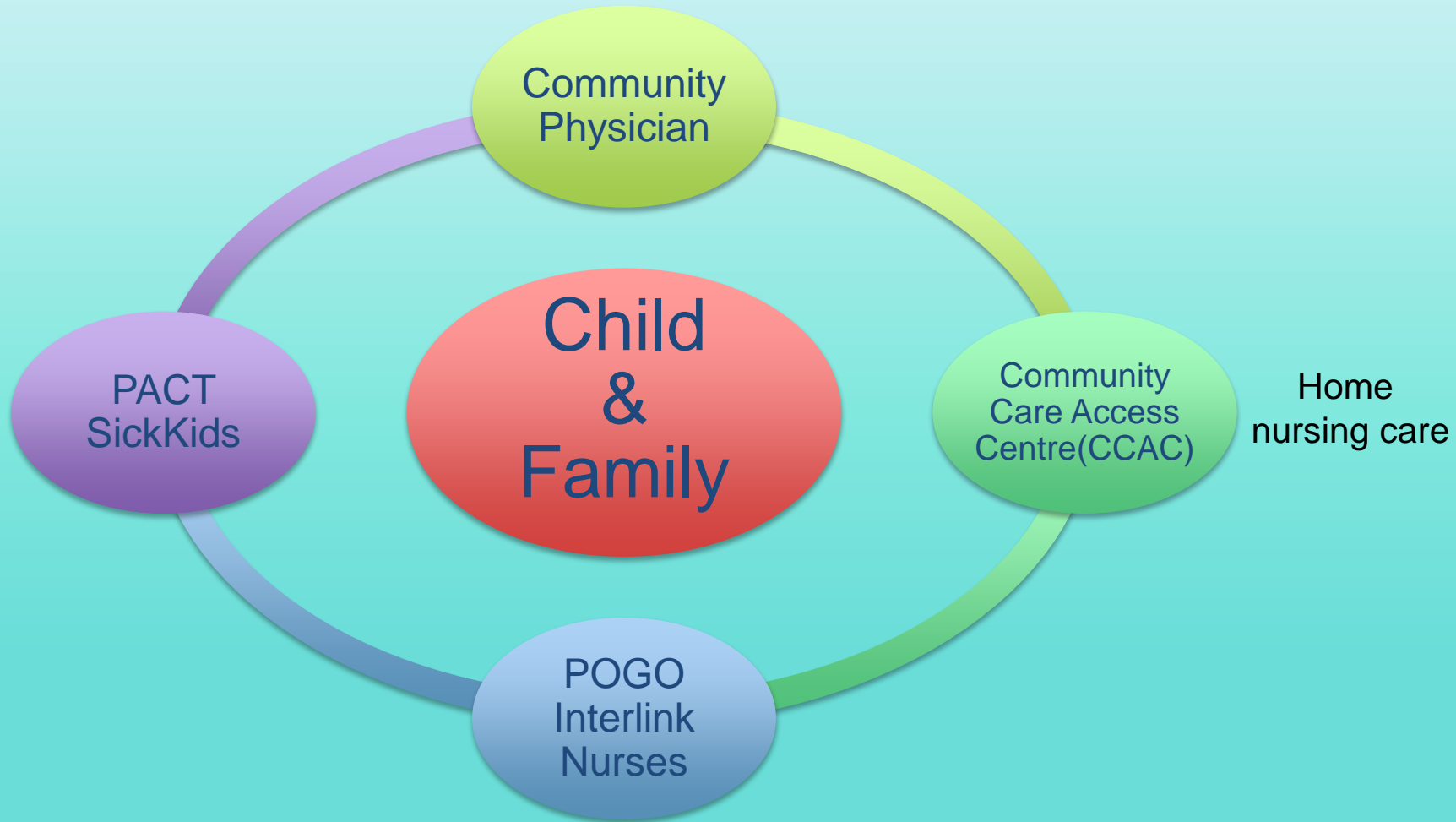
- Participants
- Diagnosis
- Reason for consult
- Brief medical history
- Family & Social history
- Physical Examination
- Goals of care
- Resuscitation
- Optimizing quality of life
- Symptom management
- Family support
- Addressing fears
- Worries
- Hopes

# Services Provided by PACT at SickKids



# In the Community

Pain and other symptoms management



Provide family support through home visits & phone calls, classroom visits, meeting with teacher, home schooling

# Paediatric Hospice Service

- Emily's house provides 10-bed residential hospice for children with life-limiting illness and their families in a home like environment
- Provides respite and palliative care as well as support for parents and siblings
- PACT physicians coverage the patients for end of life care at Emily's House









# Grief Support Program

- Making memories, finding ways to tell patient's story



Photography



Hand / Foot Print



Sound Disk



Memory Box



3D Molds



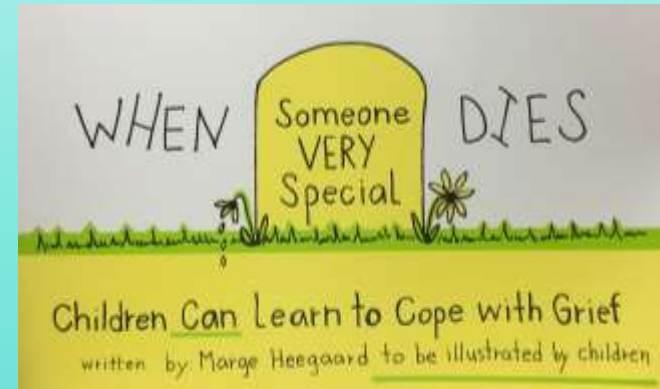
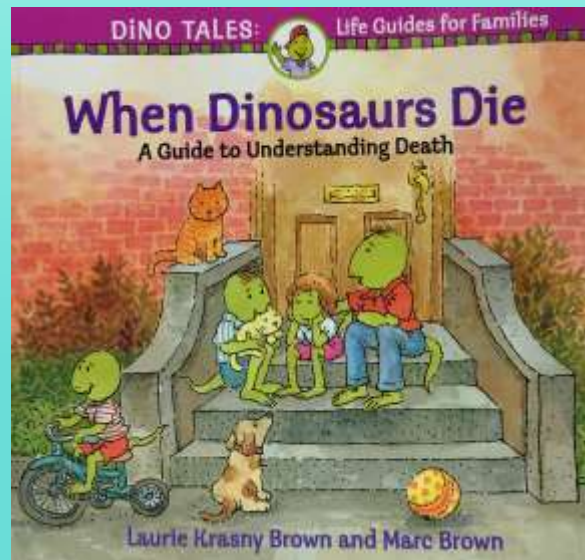
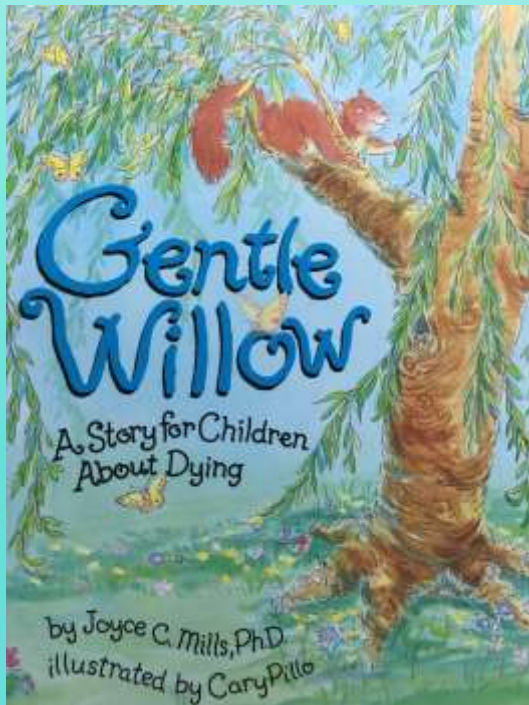
Hand Molds

# Grief Support Program

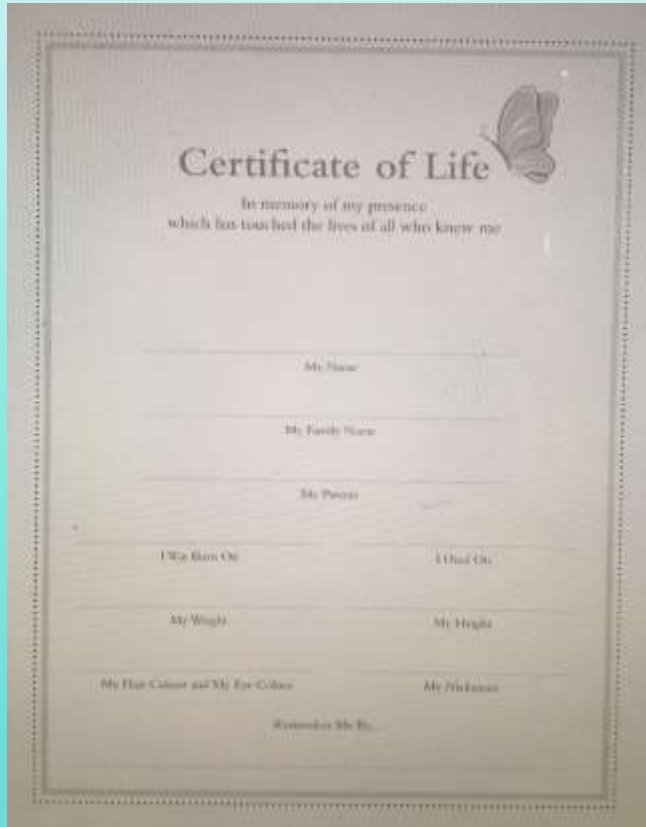
- Provide resources and information to families
  - How to plan a funeral?
  - What happens when child has died?
  - What to do with your child's belongings?

# Useful Books

Many parents struggle with how to talk to their sick child & siblings about illness. PACT provides books to help families guiding their children to understand the meaning of Death.



# Grief & Bereavement Support



Hand-calligraphy  
Certificate of Life

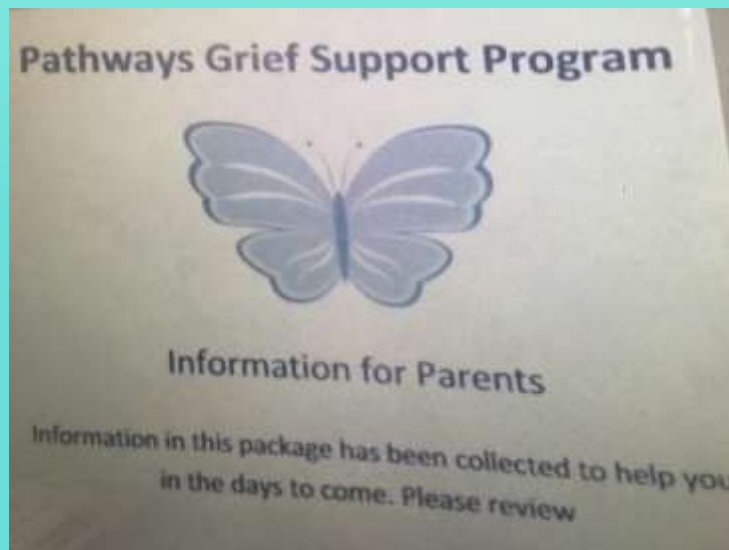
Memory Creation



Pillow or teddy bear made of  
child's clothes or blankets

# Bereavement Support

- Sending remembrance cards with supportive messages on 1<sup>st</sup> Mother's day, 1<sup>st</sup> Father's Day, 1<sup>st</sup> Birthday and 1<sup>st</sup> Anniversary
- Send mailing packages including specific written resources to support families at 1<sup>st</sup>, 4<sup>th</sup>, 7<sup>th</sup>, 11<sup>th</sup> month after child had died



# Bereavement Support

Topics of written resources included:

- ✧ *Going back to work following the death of your child*
- ✧ *Helping you and your child Grieve*
- ✧ *Things to do on the Anniversary of your Loved One's death*
- ✧ *After the first year... then what?*
- ✧ *How to remember your child on their Birthday*

# Family Events for Bereaved Families

- Picnics
- Coffee Klatches
- Camp



# Family Events for Bereaved Families



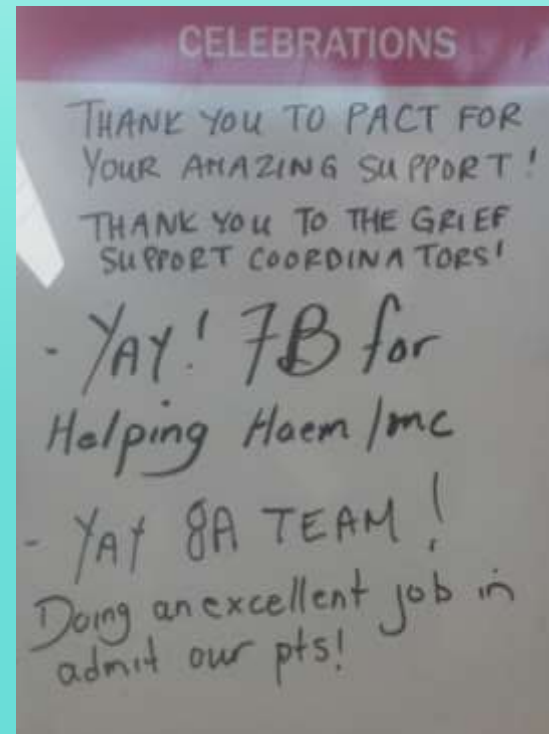
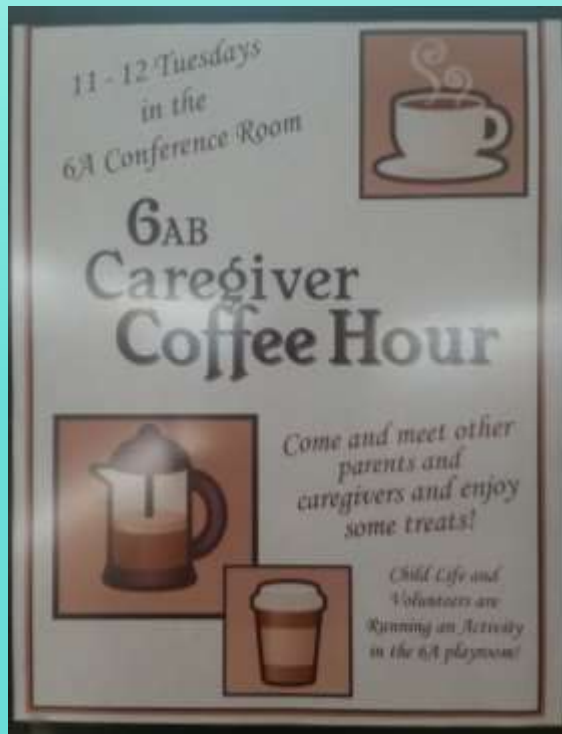
## Candle Lighting Ceremony

provides the bereaved families a chance to meet one another  
and to celebrate the life of deceased child



# Psychological Support for Staff

Debriefing session for nurses after a patient death in order to gain support and reassurance from peers while expressing their emotions, avoid burnout and poor performance.



# Application in Hong Kong

- As a consultative services
- Family-centered care
- Multidisciplinary inputs and efforts: Family input
- Respite care
- School support
- Promote community acceptance and recognition of PPC
- Extend to non-oncology patients
- Promote grief and bereavement follow up

# Limitations

- Generalize Social acceptance
- Policy support
- Human Resources:
  - Paediatric Palliative Physicians
  - Experienced health care providers
- Academic and Practical training