

Current situation and Future development: Children's Palliative Care in Hong Kong

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CPC in Hong Kong: Sept 2018

Public sector	Community sectors
Hospital Authority is the major/only service provider for children with LLC or LTCs.	Children's Cancer Foundation started the first PPC service in HK in 1999
Up to 09/2018, there is no formal structure for CPC service	All children cancer can be referred to CCF for community based PC, at home
HCW in public service asked for funding support for many years to set up a dedicated team for CPC as adult PC	Special schools are receiving more medical complex children, either as day school or residential school
2015, the first Commissioned training for PPC held in Hospital Authority	2011, Pilot programme by CCF to support non-cancer patients with PC needs
Some paediatric departments set up limited CPC service in their hospitals without additional resources	Close collaboration with HA departments and CCF on PC: doctors and nurses from HA involved.
2017 Annual Plan bidding for PPC service approved by HA (government)	HKSCPC established in 2017, and the HKCPCF in 2018



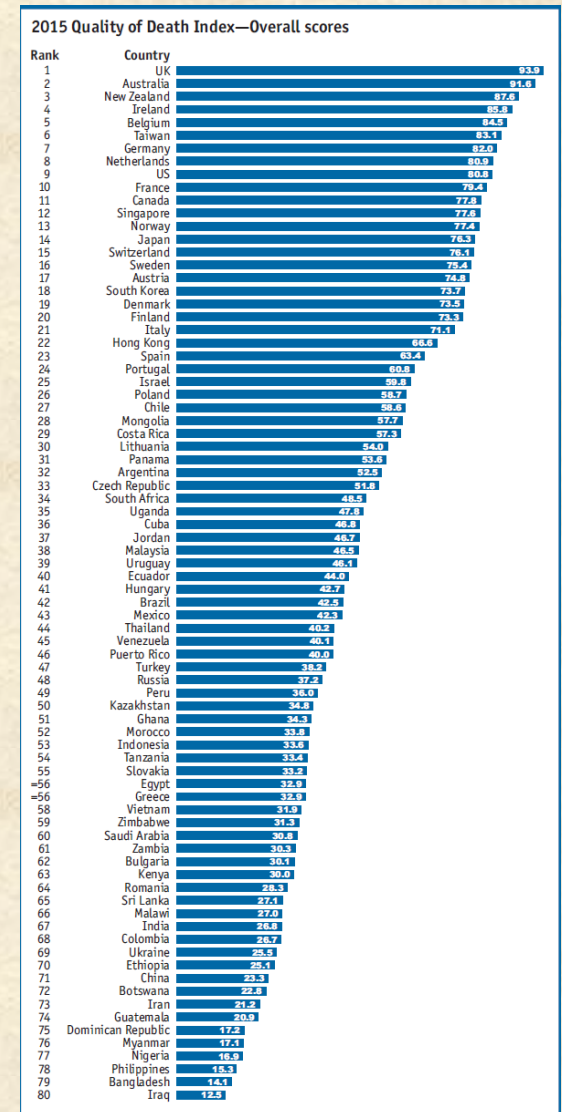


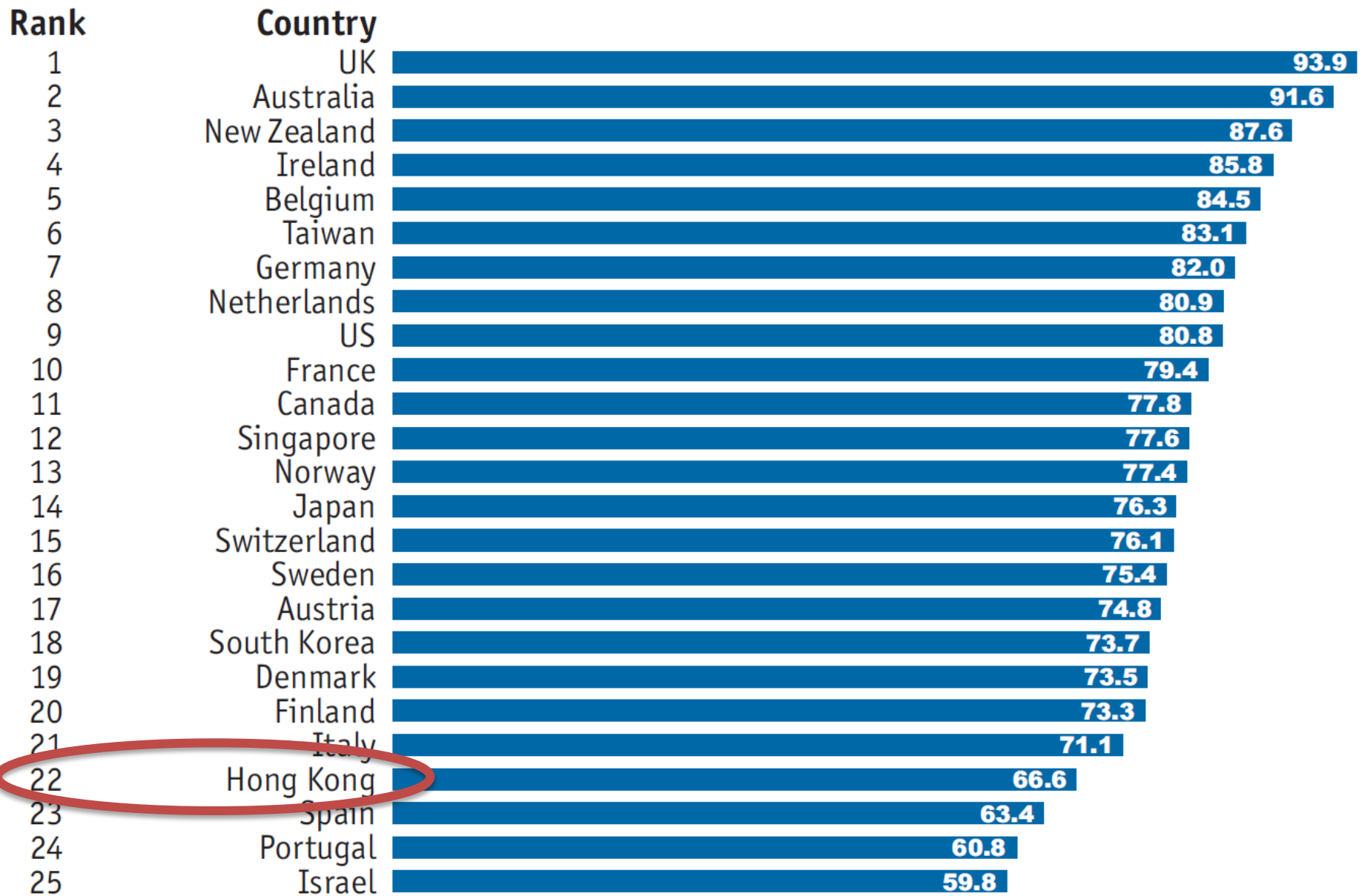
Current situation of Paediatric Palliative Care (PPC) in Hospital Authority (HA)

Palliative Care in HK

The 2015 Quality of Death index The Economist Intelligence Unit

- palliative and healthcare environment
- human resources
- affordability of care
- quality of care
- level of community engagement

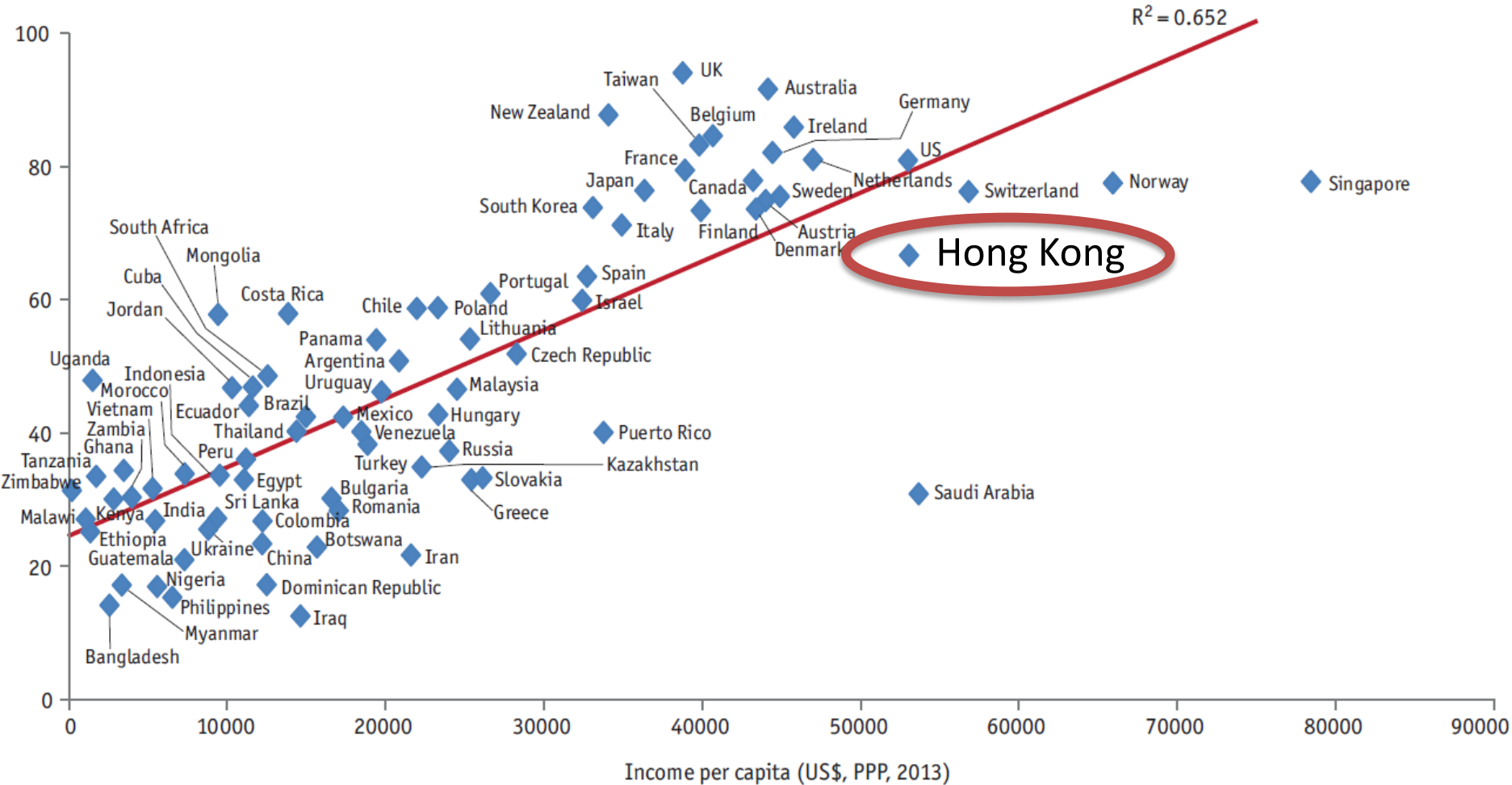




Correlation with per-capita GDP

(2013, US\$, ppp)

Quality of Death overall score (100=best)



Palliative Care service network in HA

Referral Network for Palliative Care Services



Hospital Cluster	Hospital	Address	Contact Tel / Fax
Hong Kong East	Eastern Hospital	Basement Level 2, Block East, 3 Lok Man Road, Chai Wan, HK	Tel : 2595 4051 Fax : 2976 5716
	Ruttonjee & Tang Shiu Kin Hospitals	266 Queen's Road East, Wan Chai, HK & 282 Queen's Road East, Wan Chai, HK	Tel : 9802 0100 Fax : 2838 5501
Hong Kong West	Grantham Hospital	125 Wong Chuk Hang Road, Aberdeen, HK	Tel : 2518 2100 Fax : 2873 2767
	Queen Mary Hospital	102 Pokfulam Road, HK	Tel : 2255 3881 / 2255 4649 Fax : 2255 5367
General	Hong Kong Buddhist Hospital	A1 Ward, 10 Heng Lam Street, Lok Fu, KLN	Tel : 2339 6140 Fax : 2339 6164

CLUSTER/HOSPITAL BASED Referral Networks for Adults

Kowloon			Tel : 2786 7110 Fax : 2786 2797
	Princess Margaret Hospital	2-10 Princess Margaret Hospital Road, NT	Tel : 2990 1111 Fax : 2786 3629
New Territories East	Bradbury Hospice	17 A Kung Kok Shan Road, Shatin, NT	Inpatient Tel : 2645 8802 Fax : 2636 1566 Home Care Tel : 2651 3788 Fax : 2651 3733
	Prince of Wales Hospital	30-32 Ngan Shing Street, Shatin, NT	Cancer Palliative Care Service Tel : 3505 1573
	Shatin Hospital	33 A Kung Kok Street, Ma On Shan, Shatin, NT	Inpatient Tel : 3919 7577 Fax : 2647 5461 Day Care Tel : 3919 7611 Fax : 2646 1007
New Territories West	Tuen Mun Hospital	23 Tsing Chung Koon Road, Tuen Mun, NT	Tel : 2468 5278 Fax : 2468 5276

Updated as at January 2018

Source:
<http://www.ha.org.hk/haho/ho/hac/p/122336e.pdf>

Current Palliative Care in HA

Adult

- Palliative medicine as a medical specialty in 1998
- Structured specialist palliative care teams in 16 HA hospital
- Subspecialty training

Paediatric

- By respective paed depts (no structured programme)
- No subspecialty training
- Limited community support
- Lack of structured transition care

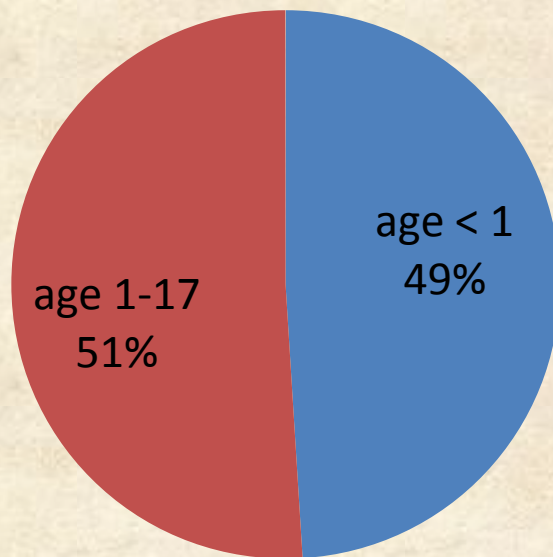
Paediatric palliative care

- Relatively low demand for paediatric palliative care compared to adults
- Uniqueness of caring for sick children
- Lack of specialized expertise and training

Relatively Low Demand for Paediatric Palliative Care

No. of registered death in HK (2014): **45 718**

- **< 1 %** (256*) are of **age < 18**
- Of which, **212 (83%) deaths occurred in HA**



Half of them occurred before the age of 1

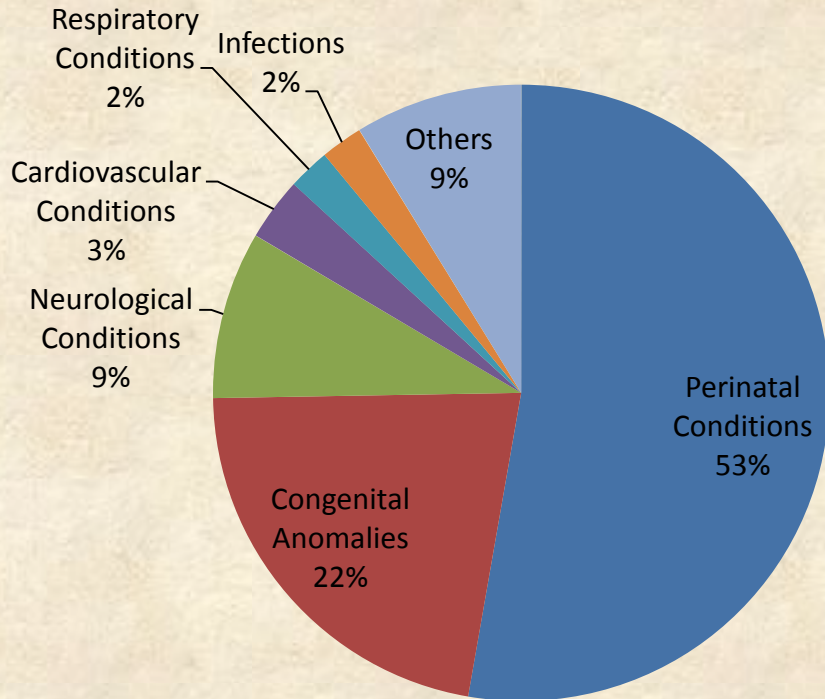
Death Location	Freq.	%
NICU	69	67
PICU	50	
ICU	3	
GEN PAE	40	26
SCBU/NUR	7	
MED/SUR/CTS/NS/MH	14	7

Among those IP/DP deaths < 18 in HA, majority in intensive care setting

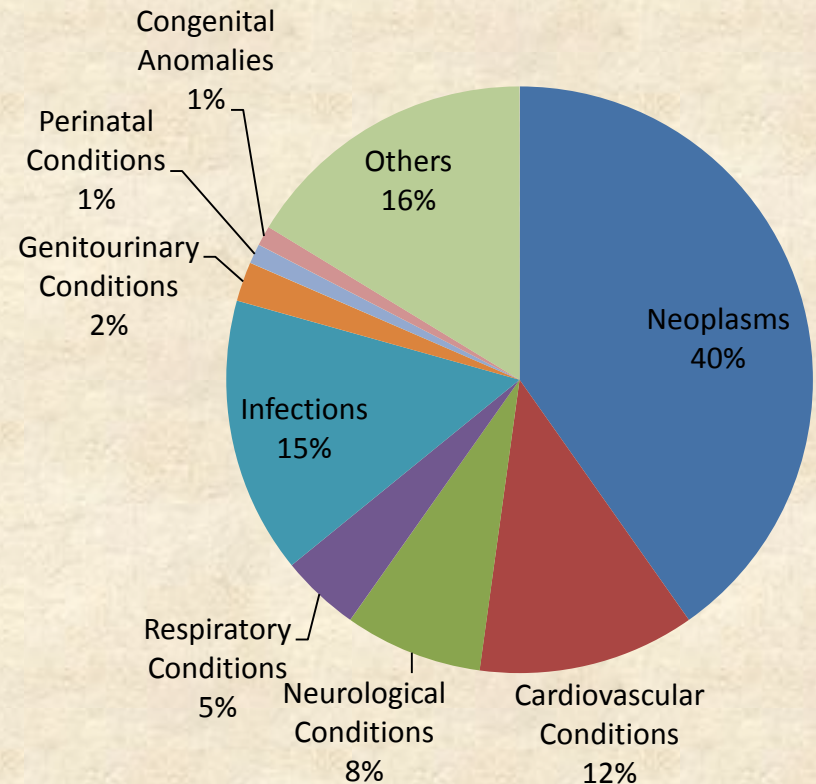
* No. of known deaths was based on death records from the Immigration Dept (up to May 2016) and HA Patient Master Index

Uniqueness of Caring for Sick Children

Death in Age Group < 1 (2014)



Death in Age Group 1 to <18 (2014)



According to the principal diagnosis of death episode in HA

Lack of Specialised Expertise and Training

- Training programme for this subspecialty has yet to be developed under the Hong Kong College of Paediatricians
 - Just proposed to HKCPaed include a mandatory training module to all trainees
- No coordinated training for nurses and allied health professionals in paediatric palliative care

Medical staff opinion: urgency for improvement

Factors needing improvement with level of urgency

Factors needing improvement	Level of urgency (Mean)*
Availability of manpower	4.20
Linkage between hospital service and community service	3.76
Sufficient resource support	3.75
Recognition of the importance of paediatric palliative care	3.70
Bereavement service for patients' families	3.69
The knowledge of palliative care among patients' families	3.68

*Range from 1 to 5, higher score means more immediate improvement is needed. Mid-point is 3.

New Hong Kong group set up to push for end-of-life care for children

Concern group's founder said such palliative care often overlooked for kids, and urged public hospitals in the city to resolve grey areas on this issue

PUBLISHED : Monday, 10 October, 2016, 10:04am
UPDATED : Tuesday, 11 October, 2016, 12:10pm



Elizabeth Cheung
Emily Tsang

A group of medical professionals have formed a new concern group to advocate end-of-life care for around 1,000 children in Hong Kong who suffer terminal illnesses such as cancer or rare diseases every year.

林鄭月娥探訪罕見病人佩珊 告知新藥將到港可免費使用 佩珊落淚



蘋果新聞 | NEXT | 飲食男女 | Ketchuper | TOMONEWS | 蘋果12 | 海外

今日蘋果 | 動新聞 | 娛樂雅台 | 即時新聞 | 周刊 | 動Live | 籽想旅行 | Easy PaMa | 健康

要聞港聞 | 2014年05月09日 | 患絕症小倩行每日親親爸媽 生命倒數愛回家

患絕症小倩行 每日親親爸媽 生命倒數 愛回家

Girl with non-curable disease going back home and kiss her parents at the end of life

AA

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【本報訊】相片中的倩行，五官精緻，被爸爸媽媽擁着親吻臉頰的她，笑得很甜。五歲的可愛女孩，去年確診罹患罕見的尤因氏瘤（Ewing's Sarcoma），骨頭、組織和肺部都有癌腫瘤，全身疼痛。倒數生命的日子，倩行在威院和兒童癌症基金合作的家居及舒緩護理服務安排下，回到家中，在熟識的環境並在媽媽的懷中，留到生命的最後一刻，今年3月安詳離世。

記者：陳凱迎

罹患尤因氏瘤的倩行，今年3月在家中安詳離世；圖為倩行生前與父母合照，兒童癌症基金提供圖片

The Chief Executive, Mrs Carrie Lam visited patient with spinal muscular atrophy

Source: <https://www.scmp.com/news/hong-kong/health-environment/article/2026539/new-hong-kong-group-set-push-end-life-care>
Source: <https://hk.news.appledaily.com/local/daily/article/20140509/18714244>
Source: <https://www.hk01.com>

Case Load Estimation on Life Limiting Conditions

Life Limiting Conditions Group	No. of patient aged <18 in 2014 ever treated as inpatient
Oncology	71
Cardiology	434
Nephrology	34
Neurology	441
Neonatology & congenital	678
Metabolic	201
Total	1859



Future development for Paediatric Palliative Care in HA



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Future development for paediatric palliative care

- 2016, formation of concern's group to push end-of-life care for children
- 2017, formation of The Hong Kong Society of Children's Palliative Care
- 2018, Hong Kong Children Hospital



The Hong Kong Society of Children's Palliative Care
香港兒童紓緩學會



Future development for paediatric palliative care

palliative care for paediatric patients can take place at **Any Stage** of a serious illness



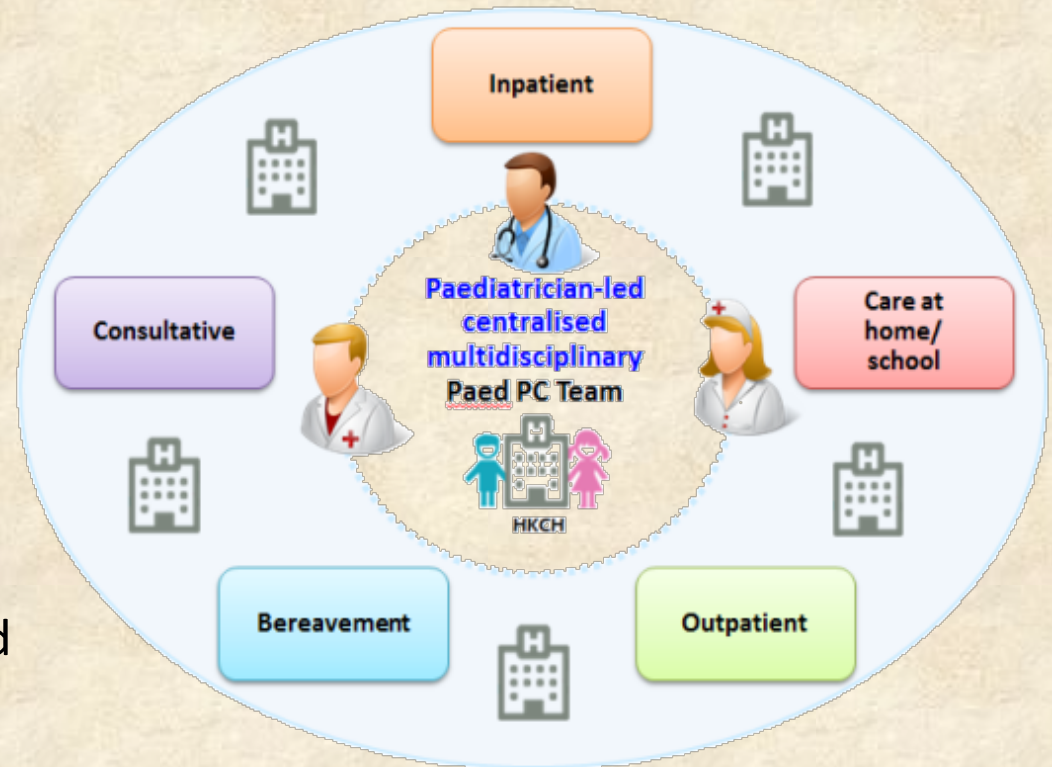
provided in **Different Settings**, ranging from tertiary care facilities to the patients' home



Families include parents, siblings, carers and significant others who matter to the patients

Territory-wide Paediatric Palliative Care Services in HA

- **Centralized Paed PC team**
- **Territory-wide service** (outreach consultation and shared care with other hospitals)
- **Inpatient, outpatient, home care, support to schools and bereavement care**
- Engage **Community** (NGOs and patient groups)
- **Transition care**



Palliative Care in HA : referral criteria

Inpatient PC

Outpatient PC

Home Care PC

Day Care PC

Inpatient
Palliative
Consultation team

Referral Criteria for Different Palliative Care Type for Advanced Progressive Disease

1. **Inpatient Palliative Care**
 - Respite care for exhausted family
 - Moderate to severe symptoms that require day to day medical intervention
 - Clinically unstable requiring in patient care
 - Complex psychosocial problems that require intensive therapy or intervention
 - Patients with advanced progressive disease requiring rehabilitation to handle activities of daily living
 - Care for the imminently dying
 - Respite care for exhausted family

2. **Outpatient Care**
 - Initial referral for:
 - ✧ Patients with advanced progressive diseases suffering from symptoms that require specialist opinion for symptom palliation
 - ✧ Complicated and unresolved psychosocial problems that relate to advanced progressive diseases
 - Continuity of palliative care of discharged patient

3. **Home Care**
 - Symptoms management that require more intensive monitoring than outpatient follow up by Home Care Team
 - Weak patient that are unable to attend out-patient clinic
 - Mild to moderate psychosocial intervention for patient and family
 - Support for family to maintain patient at home
 - Continuity of nursing care for discharged patient
 - Pre-bereavement assessment and bereavement care
 - Support patient to die at home if it is patient/family's preference

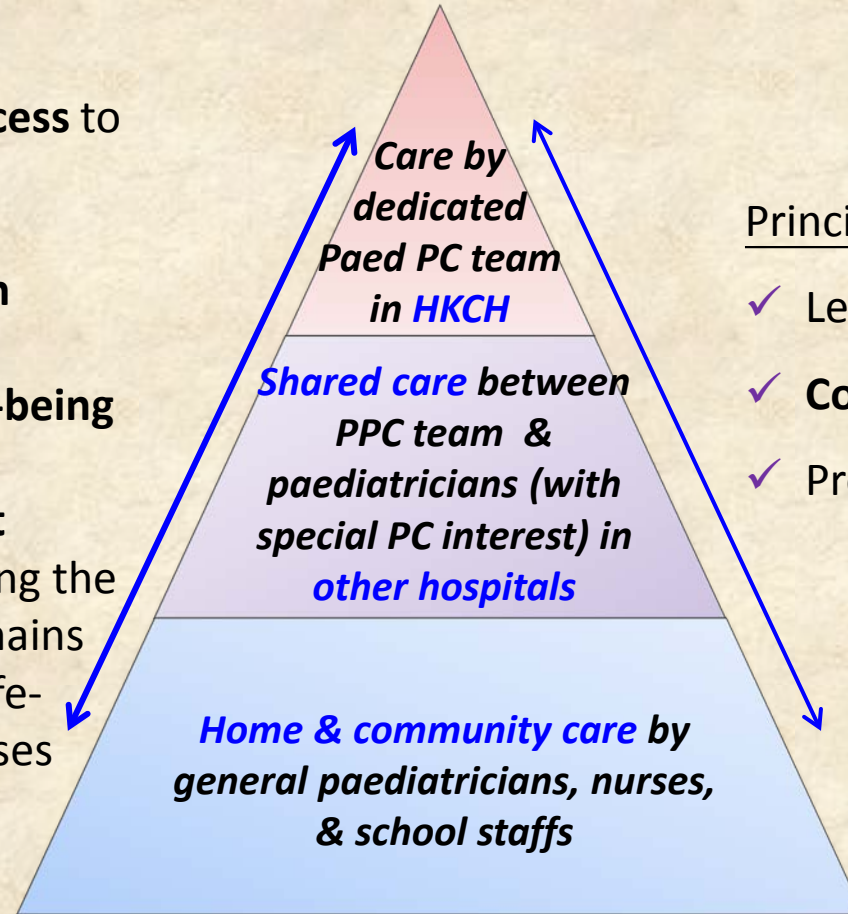
4. **Day Care**
 - Symptom that may require daily intervention but otherwise is clinically stable
 - Physically dependent patient who requires day time support but otherwise night time support could be provided by family
 - Patient/family's wish for patient to remain at home
 - Day Respite Care for exhausted family
 - Social activity to improve quality of life
 - Group or individual psychosocial care that requires less frequent intervention than inpatient care
 - Resource centre for medical equipment or patient/family education

5. **Palliative Consultative Team (In-patient)**
 - Patients with advanced progressive diseases hospitalized in acute unit who have significant symptoms or complex psychological problem that require early intervention
 - Patients with significant symptoms that require palliative specialist opinion who are still under the care of referral team
 - Patient who requires Palliative Care but psychologically not ready for inpatient palliative care referral

Integrated and Shared Care with Parent Teams

Aim:

- ✓ Facilitate early **access** to PC service
- ✓ Improve **symptom control** and psychosocial **well-being**
- ✓ **Support to parent teams** in addressing the multiple care domains of patients with life-threatening diseases



Principle of delineation:

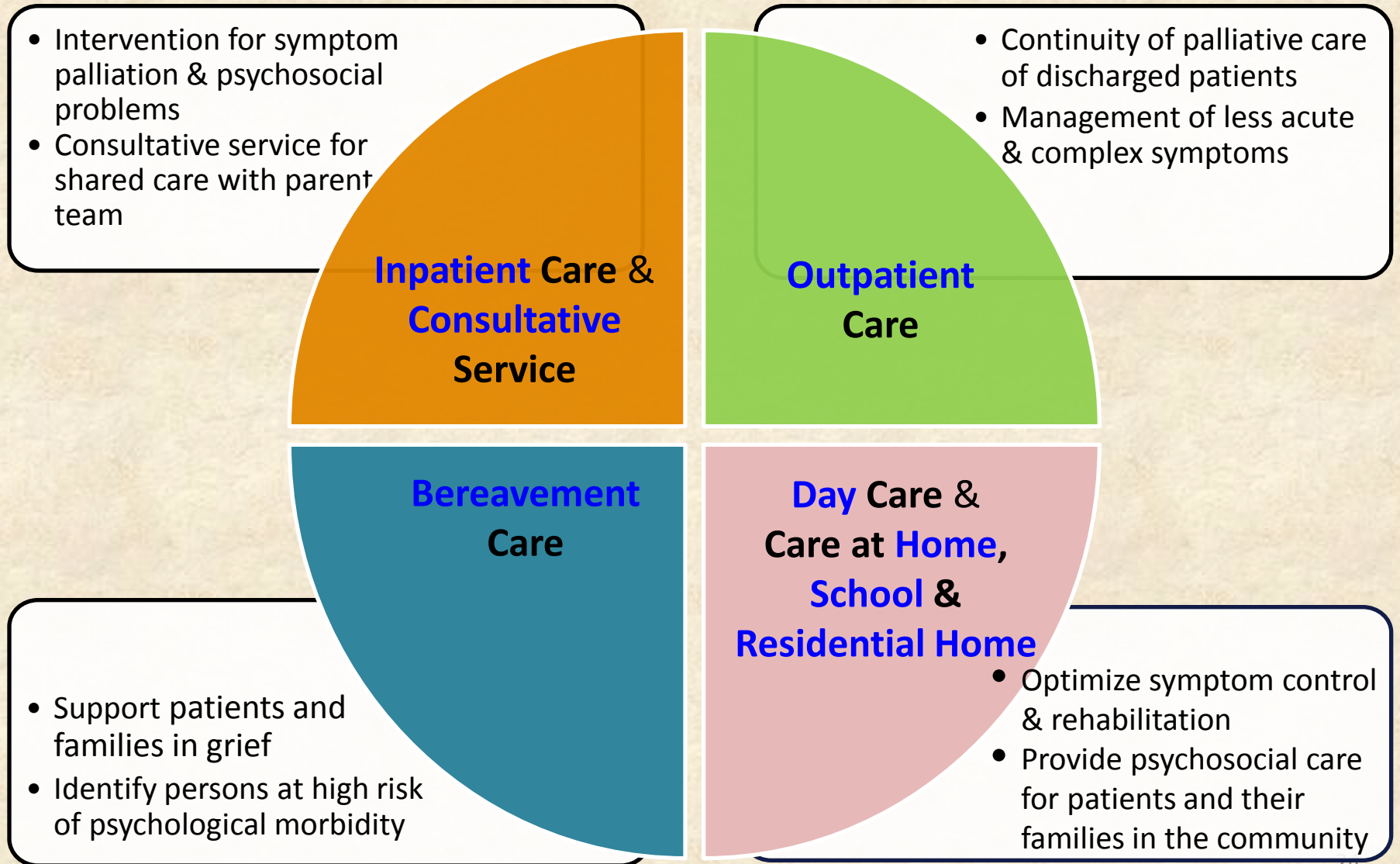
- ✓ Level of **patients' needs**
- ✓ **Complexity** of the disease
- ✓ Professional **competence**

Enhance Community Support

- Develop Paediatric Palliative **Home Care** Service
- Enhance Palliative Care Support for **Special Schools and Residential Schools**
- Strengthen **Community Partnership** on Paediatric Palliative Care



Care Continuum of Palliative Care Services



Future development for paediatric palliative care

- Development of a **specialized PC team** under paediatric specialty
- Aimed : improving the **accessibility and quality of palliative care** for chronically or seriously ill paediatric patients and their families, such that their quality of life could be enhanced





Thank you



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