

Professor Sophia Chan Siu-chee, JP Secretary for Food and Health 18/F, East Wing, Central Government Offices 2 Tim Mei Avenue, Tamar Hong Kong SAR

20 August, 2019

Dear Professor Chan,

### Re: White Paper "Towards World Class Cancer Care"

I am pleased to introduce the attached White Paper on cancer care, produced by the Healthcare Committee of The British Chamber of Commerce in Hong Kong; and to invite you to the launch of the paper.

In February 2019, the Chamber formed a sub-committee on cancer care to explore the challenges patients here face in accessing and financing cancer services, including prevention, screening and treatment. The Committee undertook a metanalysis of all patient-facing studies conducted over a twenty-year period, met stakeholders in the healthcare community including NGOs and delivery organisations, and appraised international approaches to care delivery. The findings from this study, together with proposed solutions, are outlined in the White Paper.

We are delighted that there is significant synergy between our analysis and the direction expressed by the Food and Health Bureau (FHB) in the recently launched Cancer Strategy. We take this opportunity to congratulate the FHB on the Strategy and, in doing so, signalling the significance that the Government attaches to an issue which touches – directly or indirectly – almost every citizen. Similarly, our White Paper represents the commitment of the Chamber business community to enhancing prevention and treatment efforts in order to reduce the incidence of disease, and optimise the experience of care.

The White Paper makes several recommendations which may offer a level of detail useful to the FHB when formulating the tactical plan beneath the overall strategy. Notably, we recommend the introduction of access targets to better manage patient expectations of care, with the utilisation of PPP models to reduce the time patients wait to receive diagnostics and treatment. Further, the paper suggests a new approach to the financing of high-cost cancer therapies, based on the creation of a dedicated fund for cancer drugs and the evolution of risk-backed agreements to ensure payment is made only when outcomes are achieved. Lastly, but very importantly, there are a number of specific recommendations for improving the communication between patients and caregivers and the psychological support they receive.

We plan to launch the White Paper in September, at a Chamber breakfast event open to all members of the community.

In advance of the launch, we would very much welcome the opportunity of meeting you and members of your team to discuss the paper's findings and recommendations, and the goals that we share. We would also be honoured if you could join the launch and perhaps share a few words on the overall strategy and its implications for Hong Kong.

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I again thank you for your efforts in addressing this emotive issue, and look forward to constructive dialogue on how the business community can further support development in this area.

Yours Sincerely,

Andrew Seaton
Executive Director

Audrew fech

CC: Mr. KO Pat-sing Tony. Chief Executive. Hospital Authority

Dr. CHAN Hon-yee Constance, JP. Director of Health. Department of Health

Mrs. FUNG CHING Suk Yee, Betty, JP. Head. Policy Innovation and Co-ordination Office



# The British Chamber of Commerce in Hong Kong Cancer Care Sub-Committee Working Group

Response to the Hong Kong Cancer Strategy 2019

### August 2019

### **Executive Summary**

- 1. As the Government of Hong Kong SAR move forward with planning the future of cancer services, the dimension of patient experience is an integral part of cancer strategy. Given the rising incidence of cancer and level of public concern around access and affordability, a review of patient voice and experience data is urgently needed. This submission presents the Working Group's findings on patient experience captured through a process of stakeholder engagement activities conducted during spring 2019. Members believe the recommendations contained within this White Paper are complementary to the high-level Hong Kong Cancer Strategy announced in July 2019, and have put forward concise, actionable proposals to enhance patient experience as the cancer strategy is implemented.
- 2. The dialogue around patient experience has been largely anecdotal or relating to evidence limited to a particular cancer type, however, this evidence suggests an overwhelmingly significant percentage of cancer patients encounter troublesome pain-points during the course of their care. Whilst the dimension of patient experience is less researched than other facets of cancer strategy, improving the service quality and experience of patients holds significant impact to the individual, the health sector, and our broader society.

### The Priority Areas

- 3. Through a process of data collection spanning stakeholder consultations, Working Group discussions, patient survey, and desktop review, the following system pain-points have been identified and prioritised:
  - a. Patient communication gaps and confusion
  - b. Difficulty accessing diagnostics and services because of system structure and capacity
  - c. Difficulty accessing therapies because of limited financial resources or means-testing and approval delays
  - d. Delays in and lack of care coordination

### **Our Response**

4. This White Paper sets out a programme of action areas to tackle the system pain-points as experienced by cancer patients. The action areas are arranged as short, mid, and long-term goals with corresponding KPIs.

- 5. Cancer management is currently dispersed across multiple departments in the public system, which creates service gaps and unnecessary resource wastage. The structure of the dual-track system and uncertain accountability of cancer care are currently exacerbating access and quality issues.
- 6. The Hong Kong Government is well-placed to address the system imbalance and strengthen the cancer patient pathway. Pilots in new care models, public-private partnership, and technological and workforce enablers are already in place within the public healthcare ecosystem.

### 7. Our vision is for:

- Better communication along the cancer pathway
- Improved system capacity and access to care through public-private rebalance and utilisation of untapped human and diagnostic resources
- Enhanced patient access to life-saving therapies
- A more holistic model of cancer care for Hong Kong patients
- 8. Actions to Address the Communication Gap in Cancer Care
  - a. Short-term: Employ more case managers to assist patients in navigating their care plan
  - b. Mid-term: Evolve the skillmix of delivery teams to include more medical social workers, nurses and administrators
  - c. Mid-term: Expand EHR via eHRSS to eligible NGOs who provide critical psychosocial support to cancer patients
  - d. Long-term: Medical training to improve the doctor-patient communication gap and encourage shared decision-making
- 9. Actions to Improve System Capacity and Access to Care
  - a. Short-term: Improve compliance to screening and vaccination by enhancing public education and awareness
  - b. Short-term: Employ population-wide mammography screening
- 10. Actions to Increase the Proportion of Cancers Diagnosed Early and Accurately
  - a. Short-term: Enhance the Radi Collaboration Project PPP to reduce diagnostic waiting times
  - b. Short-term: Enhance HA working hours via insourcing
  - c. Long-term: Enhance the capacity to deliver personalised cancer care via a designated Research and Development plan for comprehensive genomic profiling across cancer categories
- 11. Actions to Improve System Capacity, Allowing More Patients to Access Care
  - a. Short-term: Enhance HA working hours via insourcing

- b. Long-term: Relax the rules for admitting overseas medical personnel to practice in Hong Kong
- 12. Actions to Improve Patient Access to Therapies
  - a. Short-term: Streamline the application process for subsidy
  - b. Short-term: Offer riders for VHIS cancer care specialty products
  - c. Short-term: Expand CCF coverage to the middle-income class and lower the threshold for subsidy application
  - d. Mid-term: Set up a separate Cancer Fund and use the interest
  - e. Mid-term: Explore risk-backed agreements with pharmaceutical stakeholders to expedite patient access for drugs which have already gained safety approval
  - f. Long-term: Offer tax deductions for people who self-pay for care/therapies at accredited institutions
- 13. Actions to Move Towards a Holistic Approach to Cancer Care
  - a. Short-term: Create a fully integrated patient portal for cancer information at all stages of the patient journey, centralising public, private and community resources, and including functionality to capture feedback on services, outcomes and patient experience
  - b. Long-term: Expand the Cancer Case Manager (CCM) Programme to all cancer fields and adopt a Multidisciplinary Team (MDT) approach to cancer care

### **Next Steps**

14. Cancer strategy is a complex area for health policy and service design. To this end, a thorough assessment of cancer experience data was reviewed alongside the local market's dynamics, core strengths, and constraints. Solutions-based recommendations have been structured for timeliness, market relevance, and actionability. Short, mid, and long-term goals have been paired with corresponding KPIs to address the prioritised system pain-points reproted by patients. All strategic recommendations have been mapped against an ease-impact matrix during formulation.

#### 1: Introduction

- 1.1 In 2018, The British Chamber of Commerce in Hong Kong established a Cancer Care Sub-Committee. The objective of the Committee is to explore the challenges patients in Hong Kong face in accessing and financing cancer services, including prevention, screening and treatment. The data captured during this exploratory work has been developed into a White Paper for submission to Government to build upon and strengthen the recently-published Cancer Strategy.
- Over a three-month period, the Sub-Committee reviewed the published literature on the experience of cancer patients and their families, undertook a survey, and met with representatives from major cancer NGOs in the local market. These activities covered many aspects of cancer care: from prevention and screening, through to treatment, and access to therapies.
- 1.3 In this White Paper, we share the results of this work. We outline the areas in which Hong Kong is making good progress, identify challenges and issues facing cancer patients, and offer recommendations on solutions to address these.
- 1.4 The identified challenges fall into four major categories: communication gaps, system capacity and access to care, access to therapies, and holistic care.

### 2: The context for this study

2.1 Cancer is the leading cause of death in Hong Kong (*Fig. 1*) [1]. In roughly a decade, new cancer cases have increased by about 33% (*Fig. 2*) [2]. The escalating burden of disease and the subsequent impacts on population health are being driven by population ageing, lifestyle risk factors (such as tobacco use, diet and obesity), changing lifestyle patterns, alcohol consumption, and environmental factors.

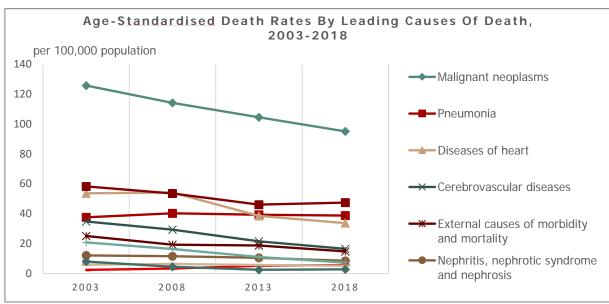


Figure 1. Cancer remains the leading cause of death in Hong Kong

Source: Centre for Health Protection

Figure 2. Leading Cancer Types, 2006 and 2016

Rank in 2016	Cancer type	No. of new cases in 2006 (rank)	No. of new cases in 2016	Overall change
	All cancers	23,750	31,468	32.5%
1	Colorectum	3,918 (2)	5,437	38.8%
2	Lung	4,233 (1)	4,936	16.6%
3	Breast	2,595 (3)	4,123	58.9%
4	Prostate	1,068 (5)	1,912	79.0%
5	Liver	1,745 (4)	1,810	3.7%

Source: Hong Kong Cancer Registry

- 2.2 Cancer affects us all. Whilst some modifiable lifestyle factors can predispose a person to developing cancer, the disease still strikes indiscriminately. In 2016, cancer claimed the lives of over 14,000 Hong Kong citizens [2]. There were 31,468 newly-diagnosed cases of cancer in 2016, an increase of 3.8% in a single year, with colorectal cancer increasing by 8% and breast cancer increasing by 5.2% [1]. Whilst we predominantly classify cancer as a disease of the ageing, half of the 2016 cases occurred in individuals under the age of 64, and 48% of all new diagnoses affected the working age population [2].
- 2.3 Although improvements have been made in both survival and mortality in recent decades, significant pain-points persist across the patient journey and this warrants our collective attention and a solutions-based approach to improving cancer care experience for Hong Kong's citizens.
- 2.4 The Government of Hong Kong SAR recognise the significance of cancer and have made positive steps towards improving screening, access to services and therapies, and treatment. However, gaps remain in the following areas:
  - There is a lack of comprehensive cancer management
  - Cancer management is dispersed across multiple departments
  - Relatively little has been done to understand the patients' experience of care
- 2.5 Many aspects of cancer have garnered attention, support and resource allocation in the form of both labour and capital. Prevention, treatment, disease surveillance, and research are familiar cancer topics to patients and stakeholders alike. Less studied, however, is the quality of cancer patient experience.

## 3: Methods

3.1 In April 2019, the Sub-Committee launched a data collection period to map patient experience and pain-points, and inform solutions for pathway strengthening. Data was

sought from the following sources: leading local cancer NGOs, patients and family members, and views from the Sub-Committee's Working Group. A systematic review and metanalysis rounded out the study activities.

- 3.2 An evidence-based approach was employed to conduct the systemic review and metanalysis, in an effort to identify and aggregate patient experience data and draw meaningful insights. This activity included studies highlighting the patient's voice about cancer prevention, screening, treatment, access and affordability in the local market. Peerreviewed academic journals, Government reports, publications and official press releases, as well as cancer patient surveys and interviews published by non-governmental organisations, were all included. Data before 2000 and studies focusing on palliative care were excluded.
- 3.3 Following the desktop review, the Sub-Committee sought stakeholder views to provide further depth and understanding relating to how cancer patients are affected by the system's pain-points. Interviews were conducted with Hong Kong Cancer Fund (HKCF), Hong Kong Anti-Cancer Society, Cancerinformation.com.hk Charity Foundation Limited, the Karen Leung Foundation (KLF), and Maggie's Cancer Caring Centre. In June, the Working Group met to review the findings from the desktop review and qualitative data from NGO interviews to inform recommendations. An online survey for cancer patients and family members has been created and will be hosted by the cancer NGOs to generate further data over time.

## 4: Findings

4.1 The sources consistently describe a similar set of problems facing patients with a suspicion or diagnosis of cancer: patient communication gaps and confusion, difficulty accessing diagnostics and services because of system structure and capacity, difficulty accessing therapies because of limited financial resources or means-testing and approval delays, and delays in and lack of care coordination. The structure of the dual-track system and uncertain accountability of cancer care contribute to these issues.

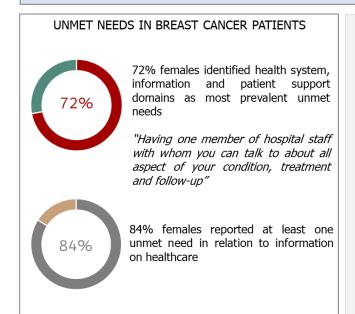
### **Communication Gaps**

- 4.2 There are unmet information and support needs amongst cancer patients. Ten local studies conducted between 2004 and 2018 focusing on breast, colorectal, nasopharyngeal and general cancer patients examined unmet information and supportive care needs, patient care satisfaction, and quality of life. The studies were employed using self-administered questionnaires or face-to-face interviews. Researchers found specific factors such as lacking information about diagnosis and treatment, shorter consultation durations, and lack of psychological support from physicians during consultations to be associated with a lower level of patient satisfaction and poorer quality of life (*Fig. 3, next page*) [3-12].
- 4.3 Nine local studies conducted between 2001 and 2017 focusing on breast, colorectal, nasopharyngeal and general cancer patients suggest that specific information and support needs vary at different points along the care pathway [7; 13-19]. For example, the

information and support needs of patients after diagnosis differ from those during the treatment process (Fig. 4, next page).

Figure 3. There are unmet information and support needs amongst cancer patients

Studies conducted between 2004 and 2018 including 2,060 breast cancer, 104 colorectal cancer, 242 nasopharyngeal cancer and 20 general cancer patients, identified the unmet information and supportive care needs, patient care satisfaction, and their quality of life using self-administered questionnaires or face-to-face



# FACTORS PREDICTING UNMET NEEDS AND THEIR IMPACT ON CANCER PATIENTS

#### Factors:

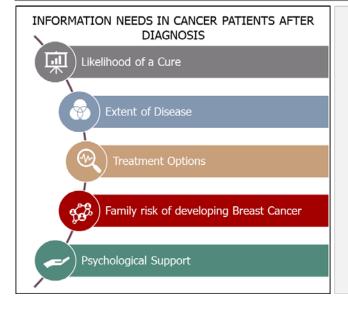
- ➤ Health System Information lack of information about diagnosis and treatment
- ➤ Question Opportunity shorter consultation durations
- ➤ Patient Support lack of psychological support from the physicians during consultations

### Impact:

Cancer patients' unmet needs are associated with a lower level of patient satisfaction with care and a poorer quality of life

Figure 4. Cancer patients have specific information and support needs along the patient pathway

Nine studies conducted between 2001 and 2017 included 881 breast cancer, 247 colorectal cancer, 211 nasopharyngeal cancer, and 436 general cancer patients, identified the unmet information and supportive care needs, patient care satisfaction and their quality of life using self-administered questionnaires or face-to-face interviews.



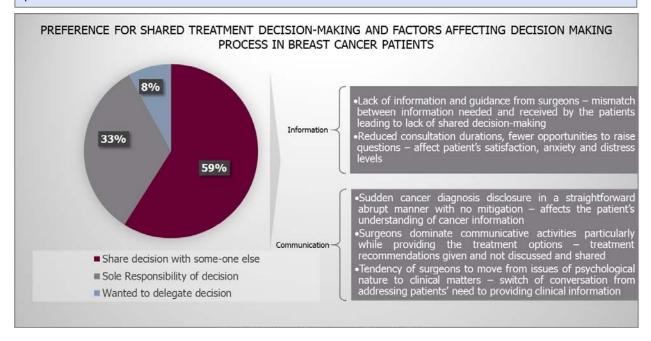
# INFORMATION NEEDS IN CANCER PATIENTS UNDERGOING TREATMENT

- · Health System Information Need
  - > Cancer Spread
  - > Treatment Information
  - > Symptom relief
  - ➤ Side-effects from treatment
  - ➤ Management of Side-effects
  - > After cancer treatment
  - > Family risk
- · Psychological Needs
  - ➤ Anxiety
  - Depression
  - > Financial Condition
- · Physical Daily Living Need
- 4.4 In the experience of breast cancer, local evidence has revealed that 84% of women reported at least one unmet need in relation to information on healthcare, whilst 72%

- identified the health system, information, and patient support domains as the most prevalent unmet needs [3, 11].
- 4.5 A further 6 studies conducted between 2003 and 2015 of breast cancer patients suggest a lack of information and closed communications between oncologists and breast cancer patients compromises the decision-making process [20-26]. Researchers found that a lack of information and guidance from surgeons results in a mismatch between the information needed and received by the patients. Reduced consultation time and fewer opportunities to raise questions were found to impact patients' satisfaction, anxiety and distress levels (*Fig. 5*) [20-26].

Figure 5. Lack of communication and closed communications compromises shared decision-making

Six studies conducted between 2003 and 2015 among 927 breast cancer patients, assessed the patients' participation in treatment decision-making and factors associated with the use of a shared decision-making process for cancer treatments.



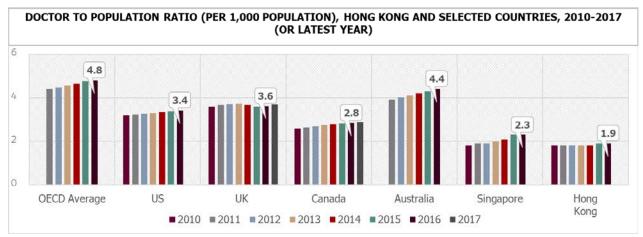
- In the context of doctor-patient communications, sudden disclosure of cancer diagnoses in a straightforward and abrupt manner has been found to affect patient understanding of the information received. Surgeons dominate communicative activities, particularly whilst providing treatment options; patients reported that treatment recommendations were given and not discussed and shared. Patients also reported the tendency of surgeons to move from issues of a psychological nature to clinical matters, and redirect the conversation to clinical information when psychosocial issued are mentioned [22-23].
- 4.7 Qualitative data from NGO interviews reinforces these findings. All respondents reported a trend of "one-way communication" and problems with the information flow between doctors and patients. NGO representatives reported that patients feel they are not allowed to raise questions or share doubts. NGO response data focused on a general lack of knowledge and awareness amongst patients. Combined, these factors lead to an environment that creates anxiety, concern and fear of the unknown amongst patients. In

such an environment, with low health literacy amongst patients and asymmetry of information in the patient and doctor relationship, informed decision-making is significantly lacking.

### **System Capacity and Access to Care**

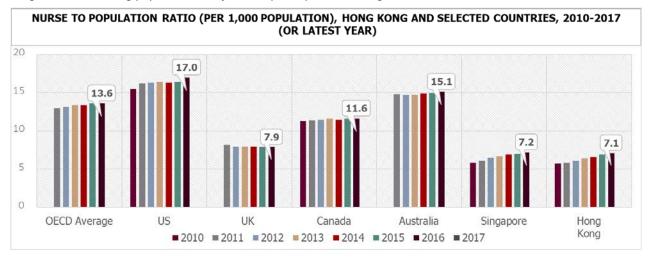
- 4.8 The public system is experiencing ongoing manpower shortages for critical medical personnel. Resultantly, system sustainability will hinge upon the ability to develop new solutions; this holds true for all specialties, including cancer care. Whilst the public system is lauded for its efficiency, it is becoming continually overstretched as healthcare utilisation is driven up by population ageing and the rise in chronic disease.
- 4.9 Hong Kong ranks lower than international comparators and the OECD average for doctor and nurse to population ratios (*Fig. 6 and 7*) [27-29]. The manpower shortage for both cadres of professionals is exacerbated by stringent licensing requirements that prevent an inflow of overseas talent.

Figure 6. Hong Kong's manpower shortage is reflected in its doctor-to-population ratio



Source: Food and Health Bureau, Singapore Ministry of Health, OECD

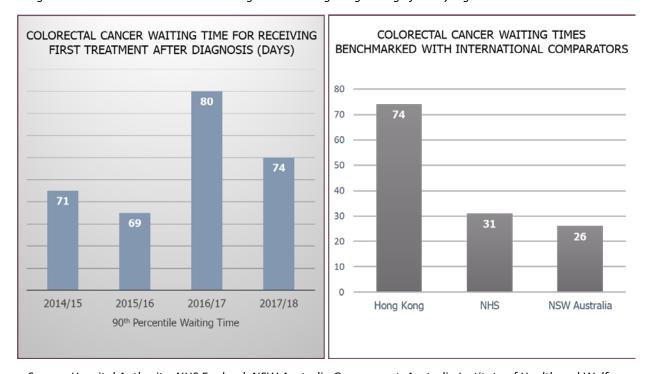
Figure 7. The nursing population also face steep manpower shortages as well as attrition



Source: Food and Health Bureau, Singapore Ministry of Health, OECD

- and staff are offered greater flexibility of working hours, but where the cost of care is outside the scope of affordability for most cancer patients.
- 4.11 For patients, this manifests as longer treatment delays and the potential for poorer health outcomes. Currently, long diagnostic wait times in HA hospitals causes a bottleneck across cancer disciplines, obstructing timely specialist consultations. At the same time, a lack of minimum waiting time targets compounds the situation.
- 4.12 In 2018, mammography wait times for the 90<sup>th</sup> percentile of patients reached as high as 973 days [30]. Unlike reference economies in Asia, including Singapore, Taiwan, Japan, Korea and Australia, Hong Kong does not employ population-wide breast cancer screening [31].
- 4.13 Regarding colorectal cancer, Hong Kong's present waiting times are significantly higher than international comparators including NHS England and NSW Australia (74:31:26 days) [32-34] (*Refer to Fig. 8 and 9*).

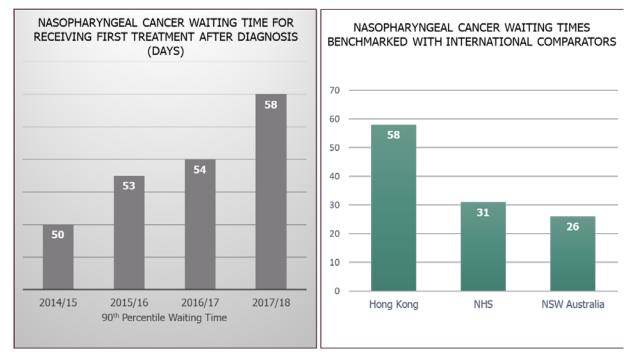
Figures 8 and 9. Colorectal cancer waiting times in Hong Kong are significantly higher than in other countries



 $Source: Hospital\ Authority,\ NHS\ England,\ NSW\ Australia\ Government,\ Australia\ Institute\ of\ Health\ and\ Welfare$ 

- 4.14 Nasopharyngeal waiting times from diagnosis to first treatment increased by 8 days from 2015 to 2018, whilst 2018 surgical wait time in days was higher than NHS England and NSW Australia (58:31:26 days) (*refer to Fig. 10 and 11, next page*) [32; 33; 35].
- 4.15 Qualitative findings from NGO response data indicated that increasing wait times cause anxiety amongst cancer patients, and ultimately impact their prognosis and survival rates. The universal view amongst respondents is that the current waiting times are simply too

long – and patients are crippled with the very valid fear that cancer will spread and metastasize.



Figures 10 and 11. A lack of minimum waiting targets often results in delayed time to treatment vs. comparators

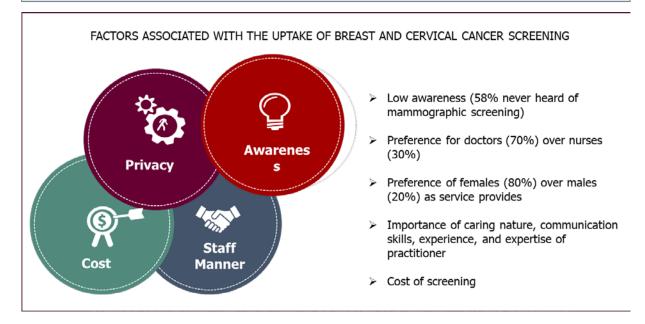
Source: Hospital Authority, NHS England, Australia Institute of Health and Welfare

- 4.16 The HA has taken steps to address systems-level capacity issues through the launch of PPP initiatives. Particularly relevant to the bottlenecks in cancer care, the Radi Collaboration Project provides CT and/or MRI services to clinically-eligible cancer patients under HA care [36]. Since its launch in 2012, patients fulfilling specific criteria have been referred to the private sector for radiological diagnostic examinations at 1 of 7 participating providers Programme participation is entirely voluntary but full subsidy is offered, and patients are afforded choice of participating service provider [37]. One of the enabling features of the programme is IT interoperability, with examination results sent back to HA through eHRSS (pending patient consent). The programme's success is rooted in its broad coverage of cancer areas, and the underpinning fee-for-service contracting model which incentivises participation by private providers.
- 4.17 Aside from structural issues like manpower and capacity, health literacy also impacts uptake of services. Generally, health literacy amongst cancer patients remains low. A 2014 study of Hong Kong women aged 50 and over showed that only 34% undertook mammography screening [38]. Despite the increasing incidence of breast cancer, the uptake rate of breast cancer screening remains relatively low, with significant variance based on where patients live -- implying a causal link to socioeconomic status.
- 4.18 Three studies conducted between 2001 and 2005 among Chinese women in Hong Kong highlighted important intrinsic and extrinsic factors associated with the uptake of breast and cervical cancer screening locally [39-42]. Intrinsic factors women's awareness and beliefs and extrinsic factors cost and practitioner discipline, were associated with the

breast and cervical screening rates [39-42]. In one instance, 58% of the study population reported they had never heard of mammogram screening (*Fig. 12*) [41].

Figure 12. Both intrinsic and extrinsic factors are associated with breast and cervical screening uptake

Three studies conducted between 2001 and 2005 among 1,494 Chinese women in Hong Kong, indicated the important intrinsic and extrinsic factors associated with the uptake of breast and cervical cancer screening in Hong Kong.



4.19 NGO response data echoes these concerns about low health literacy and how it increases the likelihood for misinformation regarding prevention and screening initiatives. NGO respondents cited the lack of comprehensive screening programs for high risk cohorts, the lack of population-wide mammography screening, and the high cost of screening in the private sector as systems-level limitations. Further findings highlight a lack of well-defined targets for diagnosis and treatment, a lack of transparent outcomes measures, and key gaps in publicly-available surveillance data – including the need for survival rate reporting across all cancer types.

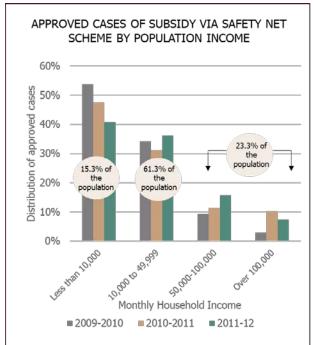
### **Access to Therapies**

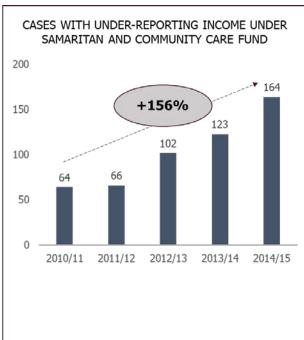
- 4.20 A number of key Government initiatives have been launched since 2005 to improve the accessibility and affordability of cancer treatments. HA implemented the Drug Formulary (HADF) that year to offer clarity to patients and prescribing doctors on drug financing inclusions [43]. The HA provides a safety net for patients with constraints in respect to specific self-financed items (SFI) through the Samaritan Fund and the CCF Medical Assistance Programmes, under which eligible patients are subsidised to purchase self-financed drugs covered by the safety net [44, 45].
- 4.21 The First Phase Programme of the CCF Medical Assistance Programmes was implemented in August 2011 to provide financial assistance to HA patients with a necessity to purchase specified self-financed cancer drugs not yet under the Samaritan Fund safety net, but

which have been rapidly accumulating clinical and efficacy data [46]. In January 2012, the Second Phase Programme was rolled out, aimed at providing subsidy to needy patients who marginally fall outside the SF safety net for the use of self-financed cancer drugs [45]. Complementing the Samaritan Fund, the Second Phase Programme provides additional subsidy to HA patients by reducing their maximum contribution ratio from 30% to 20% of annual disposable financial resources for specified self-finance items [45, 46].

- 4.22 A total of 29 self-financed drugs with demonstrated benefits were covered by the Samaritan Fund as of April 2018 [44, 46]. Among these items, 13 are for cancer treatment, of which 10 are targeted therapy drugs [44, 46]. A total of 16 self-financed cancer drugs have been covered by the CCF Medical Assistance Programmes, of which 13 are targeted therapy drugs [45, 46].
- 4.23 Whilst public reporting is limited, the data available for years 2009 to 2011 just prior to the Community Care Fund launch and immediately after suggest that middle-income earners are disproportionately affected by means-testing [47](*Fig. 13*). A trend in underreporting income in Samaritan Fund and the CCF Medical Assistance applications increased steadily from 2010/11 to 2014/15 -- 156% over a 4-year period [48](*Fig. 14*). This suggests that the stringent eligibility criteria for subsidy applications under the Samaritan Fund and Community Care Fund limit access to cancer treatment, especially in middle income earners.

Figs. 13 and 14. Middle-income earners appear disproportionately affecting by means-testing in available data





Source: Hospital Authority, Legislative Council

4.24 Qualitative data from NGO interviews supports this trend. The concern that patients have to give up targeted drug therapies for which they cannot pay, and may choose to succumb to illness rather than pay the high costs of treatments, is prevalent. Questions were raised

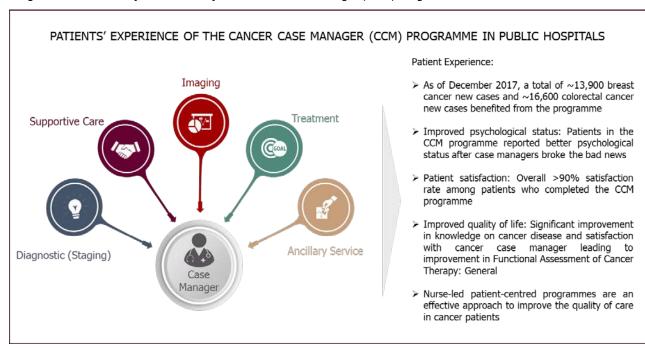
- about payment caps and voluntary copayments as vehicles to expand eligibility criteria of the current safety net provisions.
- In 2017, the Subsidy for Eligible Patients to Purchase Ultra-expensive Drugs (Including Those for Treating Uncommon Disorders) was launched under CCF [46]. In 2018, the frequency of subsidy prioritization under the Samaritan Fund and the CCF Medical Assistance Programmes was increased to twice per year, but major restructuring does not seem likely [44, 45]. The same year, Cancerinformation.com.hk Charity Foundation Limited set up a crowdfunding platform to help middle class patients access treatment [49, 50].
- 4.26 Whilst a positive step forward, the measures implemented since 2005 have often been fiscally conservative and difficult to administer. There remain considerable barriers to accessing therapies in a timely way and/or gaining funding for effective drug therapies. Patient complaints about opacity in the application process is high. Additionally, industry stakeholders cite the complicated evaluation process for drug enlistment in the HADF, Samaritan Fund and CCF Medical Assistance Programmes, which may prohibit patients' early access to specific therapies.
- 4.27 Many patients, particularly middle-income earners, suffer from a paucity of funding. The process for subsidy under CCF and SF is described as complex and stressful by applicants. Patients report being deterred by the stringent means-testing, which onerously requires disclosure of individual as well as family finances. At the same time, public awareness on cancer-related expenditure remains low and applicants would benefit from further development of information campaigns.

### **Holistic Care**

- 4.28 For patients on the current cancer pathway, pain-points exist beyond communication and access concerns. The ongoing manpower shortages and current structure of care delivery within HA have produced a pattern of doctors' rotations and system-constraints that, inturn, lead to poor patient experience of cancer care -- and ultimately prohibit the realisation of a patient-centred care model.
- 4.29 In HA, cancer service is organised and operated through 6 cluster-based clinical oncology centres, with the 7<sup>th</sup> oncology centre tentatively scheduled for commissioning by 2023 [51]. Cancer services operate as a coordinated cross-specialty and cross-disciplinary service system (including oncology, medicine, surgery, radiology, pathology, etc.) [51, 52]. However, the concept of multidisciplinary teams (MDTs), considered best practice for cancer care in many markets, is still in its infancy.
- 4.30 The importance of MDTs in cancer care is becoming widely recognised, as demonstrated by international adoption of mandatory legislation or guidelines across mature health markets. MDTs are legally mandatory or recommended in guidelines in Australia, France, the UK, Canada, Belgium and the Netherlands. Meanwhile, in Italy and Germany, it is mandatory for cancer patients to be treated in expert centres, with Germany requiring certification.

4.31 The Cancer Case Manager (CCM) Programme was launched in 2010/11 in the KWC and NWC clusters, targeting patients with complicated breast and colorectal cancer (*Fig. 15*) [51]. In 2014/15, the programme was extended to the KCC and HKEC clusters [51]. By 2014/15, the model was successfully rolled out to all HA clusters. As of December 2017, a total of approximately 13,900 breast cancer new cases and approximately 16,600 colorectal cancer new cases benefitted from the programme [51]. Patients in the CCM programme reported improved psychological status, overwhelming patient satisfaction, improved quality of life [51]. Local research suggests nurse-led patient-centred programmes, such as the CCM, are an effective approach to improve quality of care in cancer patients [53-56].

Figure 15. Overview of the success of the Cancer Case Manager (CCM) Programme



- 4.32 Whilst high-intensity and vulnerable patient populations benefit from continuity of care, cancer patients outside the scope of CCM programme experience care gaps and inadequacies. A 2002 study on follow-up cancer care demonstrated a lack of clear guidance and support regarding the management of after-effects of cancer treatments and surveillance against cancer recurrence [57] (*Fig. 16, next page*). Though nearly two decades have passed since the study date, the cancer pathway today remains fraught with similar findings: lack of psychosocial interventions, unstandardized surveillance guidelines, discrepancies in surveillance practice across hospitals, barriers to doctor-patient communication, and a lack of continuity in care provision stemming from doctor rotations.
- 4.33 As the medical workforce of a health system is an enabling feature of MDTs, the discussion in Hong Kong has often centred upon the physician and specialist shortage. However, review of relevant data across select markets indicates that Hong Kong's total oncology manpower (as calculated in Territory-wide aggregate) is on par with ratios in the UK and Australia markets, where MDTs have been widely implemented (*Fig. 17, next page*) [58-67]. The public-private divide for workforce distribution, however, remains a salient problem in the Hong Kong market. Currently, caseload distribution skews heavily towards

the public system, whilst oncologists in private settings have much lower caseloads. The misaligned distribution of workforce and patient volume between public and private is increasing system imbalance and exacerbating access issues. Future planning of cancer services and the successful expansion of local market's CCM programme will need to take this into account and explore ways to make better use of system-wide manpower resources.

Figure 16. Doctors' rotations and system constraints lead to gaps and inadequacies in follow-up care

A study conducted in 2002, on follow-up cancer care among 41 cancer patients, showed that there is lack of clear guidance and support regarding the management of after-effects of cancer treatments and surveillance against cancer recurrence.

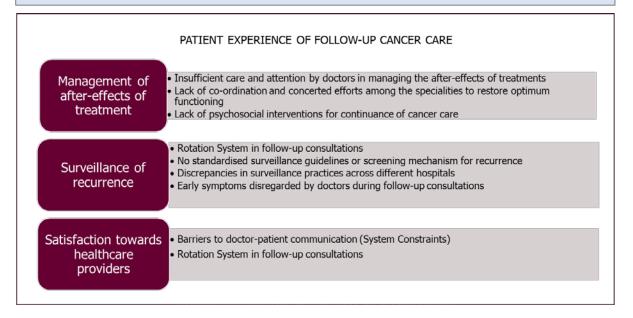


Figure 17. Hong Kong's total oncology manpower relative to select markets where MDTs are employed

Country	Year	Annual Cancer Incidence, No.	Annual Cancer Morality, No.	Mortality	No. of Oncologists	Definition for Oncologist Specialties	Ratio of New Cases Per Oncologist
Australia	2016	145,000	46,003	0.32	913	Medical and Radiation Oncologists	134
United Kingdom	2016	363,484	164,000	0.45	1,472* 2017 data	Medical and Clinical Oncologists	222
Hong Kong	2016	31,468	14,209	0.45	186* 2018 data	Medical and Clinical Oncologists	169

Source: Australian Institute of Health and Welfare, 2012 and 2019; Cancer Australia; Australian Government Department of Health; Cancer Research UK; The Royal College of Radiologists; Hong Kong Cancer Registry, Hospital Authority; Medical Council

4.34 A second topic that is relevant to growth of the CCM model of care is the current skillmix of cancer teams; in external markets where MDTs are employed, nurse case managers,

- social workers, and administrators play an increasing role in care coordination and delivery. These fields should be prioritised for growth as part of Hong Kong's overarching cancer strategy.
- 4.35 Progressing towards a more holistic model of patient care, which embeds patient centricity and care continuity, would elevate cancer care to the ranks of advanced health systems worldwide.

### 5: Strategic Recommendations

5.1 Solutions-based recommendations have been formulated after thorough review of cancer experience data. Careful attention has been paid to the local market's structure, core strengths and constraints, to ensure recommendations are timely, relevant and actionable. Each system pain-point has been linked to objectives and strategic recommendations, which were mapped against an ease-impact matrix during formulation. Corresponding KPIs are included in the table on pages 24-25.

### **Communication Gaps**

- 5.2 Objective 1: Close the communication gaps that exist in cancer care
  - a. Short-term: Employ more case managers to assist patients in navigating their care plan
- 5.3 The communication gaps that exist in the current system stem from a number of factors including low health literacy, asymmetry of information, rotation of doctors, and poor continuity of care. The role of the case managers is to ensure patient needs are met, coordinate information, and bridge the communication gap between patients and healthcare professionals. This is an aspect of cancer care that patients respond positively to, and expansion in the short-term is recommended.
  - b. <u>Mid-term: Evolve the skillmix of delivery teams to include more medical social workers, nurses and administrators</u>
- Health systems across markets are relying on different cadres of healthcare personnel to address the clinical, physical, psychosocial and administrative needs of high-intensity patients. As workforce shortages continue for key personnel like doctors and nurses, care teams with a more diverse skillmix address a wider breadth of patient need (including the non-clinical), help to offset capacity issues, and may be strategically grown through incentivised education programmes in collaboration with local universities. Given the predominance of doctor-led care models and the nascent market for several allied health professions in Hong Kong, this is a recommendation for the mid-term.
  - c. <u>Mid-term: Expand EHR via eHRSS to eligible NGOs who provide critical psychosocial</u> support to cancer patients

- 5.5 The leading cancer NGOs play a vital role in providing health education and psychosocial support to cancer patients. However, these organisations operate outside the scope of the patient's official treatment plan. Many NGOs employ full and part-time staff with clinical and allied health credentials. It would stand to reason that NGOs could be community partners in provision of care concerning psychosocial support. Similar to private providers who participate in the Radi Collaboration Project and address a single aspect of care, NGOs would benefit from access to the eHRSS, to facilitate information exchange, and drive efficiency in planning, follow-up, and community referral. With the continued expansion of eHRSS to non-HA settings and the relative ease to action this recommendation, it is suggested for the mid-term, provided due-diligence is undertaken.
  - d. <u>Long-term: Medical training to improve the doctor-patient communication gap and encourage shared decision-making</u>
- One of the most-cited problem areas for cancer patients is communication with oncologists and surgeons. Medicine has historically been driven by a paternalistic model of care and asymmetry of information has dominated for decades, but medical institutions and educational bodies have recently begun reimagining information exchange in clinical models. As shared decision-making gains traction in cancer services and medicine generally, further medical training will be required to strengthen doctors' communication skills, particularly with high-intensity patients who have psychosocial needs. Given the timeline of medical education and the constraints around launching medical course curricula, this is a less easy recommendation to implement, but one that will have high impact on patients and therefore is being suggested as a long-term action area.

### Capacity / Access to Care

- 5.7 Objective 2: Improve population-wide coverage and uptake of cancer screening
  - a. <u>Short-term: Improve compliance to screening and vaccination by enhancing public education and awareness</u>
- All evidence suggests that health literacy is generally low amongst cancer patients, with variances for socioeconomic status. In addition to structural issues like capacity and access, health literacy and low awareness influences uptake of prevention and screening services. The Hong Kong Government has a strong history in public health campaign and disease awareness, and can leverage this skillset with relative ease to enact high-impact, targeted public education and awareness initiatives.
  - b. Short-term: Employ population-wide mammography screening
- 5.9 Hong Kong has the capability and expertise to roll out quality, large-scale population screening programmes. Whilst the case of mammography has been at times emotive, controversial and culturally sensitive, other developed Asian countries have examined the scientific evidence and transitioned to population-wide screening programmes. These include Taiwan, South Korea, Japan, Singapore and Australia. Screening improves cancer

- detection, reduces mortality, and improves patient outcomes. It has been ranked as a high-impact recommendation.
- 5.10 Objective 3: Increase the proportion of cancers diagnosed early and accurately
  - a. Short-term: Enhance the Radi Collaboration Project PPP to reduce diagnostic waiting times
- 5.11 Since its inception in 2012, the Radi Collaboration Project has been widely successful. Private healthcare facilities provide approximately 70% of all primary care in Hong Kong, and many are working well-under capacity, whilst HA services are overstretched. Initiatives like PPP, which redress aspects of system rebalance, have been adopted throughout health systems at all stages of development. Locally, a lack of trust in private services, particularly around quality concerns and fiscal transparency, has resulted in high-intensity patients remaining under HA for case management. However, outsourcing straightforward services like diagnostic testing carries reduced risk. Interoperability with the eHRSS and a fee-for-service payment structure have been the enabling features of the Radi Collaboration's success. Given population demand and the growing burden of cancer, the PPP can be expanded beyond the existing 7 providers, and higher patient volume would provide HA leverage to rethink financial contracting levers and ensure efficiency.
  - b. Short-term: Enhance HA working hours via insourcing
- 5.12 Whilst not mentioned in the academic literature, anecdotal evidence suggests patient frustration about HA delays in relation to bottlenecks. Settings and diagnostic equipment are available and could otherwise be used for specialist consultations were it not for manpower shortages. A trend observed in the UK and other reference markets is insourcing of practitioners from the private sector. This could be implemented with ease and have a broad impact in reducing diagnostic delays.
  - c. <u>Long-term: Enhance the capacity to deliver personalised cancer care via a designated Research and Development plan for comprehensive genomic profiling across cancer categories</u>
- 5.13 In addition to imaging and diagnostics tests to confirm type of cancer mutation, it is increasingly important for health systems to invest in the science behind innovations that form the basis of personalised cancer care. As healthcare and the biological sciences evolve, expertise in different disciplines have converged, accelerating scientific progress in the realm of personalised medicine. As these new trends advance human understanding of the biology of disease, data capture and the power of real-world evidence become all the more valuable. The current movement toward comprehensive genomic profiling has the potential to improve the early diagnosis and treatment options for hundreds of diseases that fall under the category of "cancer". Recent advances in genomic technology have led to considerable improvement in our understanding of the molecular basis that underpins cancer biology. Through the use of comprehensive genomic profiling, an unprecedented bulk of data on driver mutations, key genomic rearrangements, and mechanisms on tumour evolution has and will continue to be generated. The value of this data is manifold: it provides insights and invaluable information to inform cancer diagnosis, best treatment options tailored to each patient, and can inform future R&D investments. It has been noted by the Working Group that over 40 cancer-related projects were funded by the Research

Grants Council in 2018. At the same time, Hong Kong Science Park provides an ecosystem for development of early detection technologies and clinical trials. It is recommended that Hong Kong's long-term cancer strategy incorporate a designated Research and Development plan for comprehensive genomic profiling, which can be linked to the proposed Strategic Service Framework for Genetic and Genomic Services – which, over time, can be expanded beyond high-risk groups and hereditary cancer types, to eventually include broader cancer categories. Modelling after reference markets, patient participation should be voluntary for these initiatives.

- 5.14 Objective 4: Improve system capacity, allowing more patients access to cancer care
  - a. Short-term: Enhance HA working hours via insourcing
- 5.15 Similar to the recommendation for diagnostics, an insourcing model could be implemented to allow private specialists to play a greater role in cancer care provision across the treatment spectrum.
  - b. <u>Long-term: Relax the rules for admitting overseas medical personnel to practice in Hong Kong</u>
- 5.16 With the ongoing workforce shortages and escalating population demand, there is manifest need to revise the existing barriers that exist for licensure of doctors and nurses. A system similar to Singapore's regulations should be explored, e.g. graduates from the top 50 medical and nursing programmes worldwide meet inclusion criteria. Whilst Hong Kong has several market forces that could enable it to be a hub for medical innovation, current policies regarding licensing and internship requirements prevent a much-needed infusion of overseas professionals to ease the manpower shortage and fill senior consulting roles within specialties, including cancer care.

### **Access to Therapies**

- 5.17 In the case of cancer therapies, there is no one-size-fits-all solution to financing cost. Over time, technologies evolve, research improves, and costs of therapies vary for a number of market conditions. As populations and economies grow, there is an increasing need to create more efficient and effective funding mechanisms, which allow patients access to life-saving therapeutics without being driven into poverty. These critical funding mechanisms, which increasing equity and access amongst patients, frequently require regular review and restructuring. The Working Group has tailored the following financing recommendations to Hong Kong's dual-track system, its existing safety nets, and the innovations that have been made in the financing space.
- 5.18 Objective 5: Improve patient access to therapies
  - a. Short-term: Streamline the application process for subsidy
- 5.19 There are inherent deterrents in the current application processes under the Samaritan Fund and CCF Medical Assistance Programmes. Stringent means-testing and the onerous process of disclosing individual and family resources in a lengthy application is prohibitive

in nature and data indicates the high level of stress it caused to applicants. Adopting a streamlined application process which links eligibility criteria to IRD tax filing status would have a broad impact to alleviate lengthy and timely paperwork. References for this include safety net and social welfare programmes in comparator markets, e.g. the Children's Health Insurance Program (CHIP) under the Medicaid programme in the United States, where eligibility is linked to tax and income status.

### b. Short term: Offer riders for VHIS cancer care specialty products

- 5.20 The launch of VHIS this year creates an opportunity to formulate new cancer care speciality products, that offer higher levels of protection than base coverage. Under current product limits, cancer protection is modest and patients will likely utilise HA services given the tremendous likelihood of shortfall in private care settings, where price opacity and ultrahigh costs of care persist. Many of the market's leading insurers have/will create VHIS topup or specialty plans, so stimulating the insurance sector to develop cancer specialty products which have lower likelihood of use than general insurance plans could be undertaken with relative ease. This would provide greater safeguards to patients who have the means to purchase private coverage but currently lack appealing options.
  - c. <u>Short term: Expand CCF coverage to middle-income class and lower the threshold for subsidy application</u>
- In early 2019, Government and the HA introduced measures to enhance the means-test mechanism, including a modified subsidy calculation and refining the definition of "household" adopted in the financial assessment. Further to this, the CCF Medical Assistance Programmes could be expanded to middle income earners and the threshold for subsidy application could be lowered, all whilst offsetting a portion of costs by implementing a sliding co-payment system based on income and ability to pay. Payment caps have been repeatedly referenced when discussing low-income patients, but there is an untapped segment of middle-income earners who can and would finance a portion of their care if the subsidy schemes employed more innovative structuring.
  - d. Mid-term: Set up a separate Cancer Fund and use the interest
- 5.22 Given the fiscal constraints of the safety net schemes, we propose by a designated Cancer Fund that would provide more flexibility for financial restructuring over time (as population demands rise and therapies evolve). The interest generated by the fund could be reinvested as a continual revenue stream to support access and protection of vulnerable, high-intensity patients.
  - e. <u>Mid-term: Explore risk-based agreements with pharmaceutical stakeholders to expedite</u> patient access for drugs which have already gained safety approval
- 5.23 As a strategy to alleviate the financial burden of cancer patients, the HA has been in close liaison with pharmaceutical stakeholders to discuss alternative financing schemes, including compassionate programmes and risk-sharing arrangements. Risk-sharing arrangements for cancer therapies have gained traction in specific European countries, namely Portugal, Sweden and the UK. Risk-sharing models like the managed access

arrangements in the NHS are increasingly used to finance innovative oncology drugs, with an aim to ensure better budgetary control and lower risk of spend whilst evidence of clinical benefit is generated. A prominent limitation of these arrangements is when the structure is financial in nature and not based on clinical outcomes. A second limitation occurs during implementation (which can be costly) when information to support information-sharing is lacking. Risk may skew disproportionately towards the pharmaceutical stakeholder, but the pharmaceutical stakeholders in Hong Kong are open to further discussions with Government. For these reasons, it stands that a PPP model may be a viable in the Hong Kong context, providing adequate structure and due diligence. PPP models can be readily adapted to outcomes-based financing and the existing eHRSS system for HA data-sharing and collection is already in place in the context of current PPP initiatives. Whilst still evolving globally as a concept, this recommendation could ameliorate access issues in relation to high-cost, innovative medicines.

- f. <u>Long-term: Offer tax deductions for people who self-pay for care/therapies at accredited</u> institutions
- The cost of care in the private market remains exorbitantly high, even for those who can afford to finance services via private insurance and out-of-pocket payment. As individuals with the means to move to private care and lessen the capacity burden in the public system, it stands to reason that they should be incentivised via a tax deduction, similar to the provisions in place for VHIS, which was also designed to redress system imbalance. Provisions could be put in place to ensure quality, e.g. a shortlist of accredited institutions who deliver care to a quality standard approved by HA clinical guidelines.

### **Holistic Care**

- 5.25 Objective 6: Move towards a holistic approach to cancer care that focuses on patient experience
  - a. Short-term: Create a fully integrated patient portal for cancer information at all stages of the patient journey, centralising public, private and community resources, and including functionality to capture feedback on services, outcomes and patient experience
- 5.26 Data has established that patient experience is the least prioritised aspect of cancer strategy in the current system, yet an area that has direct and tangible relevance to patients irrespective of age, sex, gender and socioeconomic status. As issues of communication gaps, access, and low health literacy persist, the development of a space entirely devoted to patient need is a strong first step towards holistic care. This recommendation could be actioned as a fully-integrated patient portal that aligns public, private and community resources, is integrated into the Government's digital and technology initiatives, and provides the infrastructure for data capture on a rage of cancer experience indicators that are not presently captured in HA's acute care survey. The impact on patient experience would be tremendously positive.
  - b. <u>Long-term: Expand the Cancer Case Manager (CCM) Programme to all cancer fields and adopt</u> <u>a Multidisciplinary Team (MDT) approach to cancer care</u>

5.27 The evolution towards MDTs is gaining traction throughout mature health systems, supported by evidence of improvement across a wide range of clinical quality indicators. In Hong Kong, the CCM Programme has had overwhelmingly positive results since its inception. The CCM Programme successfully established a single contact point between patients and an MDT to streamline the care pathway, support patient needs, and improve care coordination. Beyond breast and colorectal care, it will be an essential tool towards establishing the holistic care model cancer patients deserve.

### 6: Conclusion

6.1 The Working Group believe in the strength and actionability of these recommendations to improve the patient experience of cancer care services in Hong Kong. Local market data, stakeholder engagement, and health system analysis reveal core aspects of Hong Kong's heath system that can serve as a blueprint for the recommendations contained within this White Paper. Pilots in new care models, public-private partnership, and technological and workforce enablers are already in place within the healthcare ecosystem. These health system features, which have been highlighted as core strengths of the Hong Kong market, can be harnessed to improve cancer care services, strengthen the care pathway, and address system pain-points -- thereby improving patient experience and outcomes.

# Strategic Recommendations for Improved Cancer Experience and a Strengthened Patient Pathway

Pain-Point	#	Objective	Timeline for Recommendations	Suggested KPI
N/A		Improve disease surveillance reporting	Short-term:  a. Bring Hong Kong in line with international comparators by publishing survival data for all cancer types	Survival rate reporting for all cancer types
Communication Gaps	1	Close the communication gap that exists in cancer care	Short-term:  a. Employ more case managers to assist patients in navigating their care plan  Mid-term:  b. Evolve the skillmix of delivery teams to include more medical social workers, nurses, and administrators  c. Expand EHR via eHRSS to eligible NGOs who provide critical psychosocial support to cancer patients  Long-term:  d. Medical training to improve the doctor-patient communication gap and encourage shared decision-making	<ul> <li>Percentage of patients         receiving a Treatment         Summary and Care Plan</li> <li>Percentage of patients         reporting they had knowledge         and support to make         decisions</li> <li>Percentage of patients         reporting they had         opportunities to ask questions</li> </ul>
Capacity / Access to Care	2	Improve population- wide coverage and uptake of cancer screening	Short-term:  a. Improve compliance to screening and vaccination by enhancing public education and awareness  b. Employ population-wide mammography screening	Cancer screening uptake and population coverage rate
	3	Increase the proportion of cancers diagnosed early and accurately	Short-term:  a. Enhance the Radi Collaboration Project PPP to reduce diagnostic waiting times  b. Enhance HA working hours via insourcing c. Long-term: Enhance the capacity to deliver personalised cancer care via a designated Research and Development plan for comprehensive genomic profiling across cancer categories	<ul> <li>Waiting time from first suggestive symptom to definitive diagnosis for all cancers</li> <li>Percentage of colorectal, breast, and lung cancers diagnosed at Stage I, II and III</li> </ul>

# Strategic Recommendations for Improved Cancer Experience and a Strengthened Patient Pathway (con't)

Pain-Point	#	Objective	Timeline for Recommendations	Suggested KPI
Capacity / Access to Care	4	Improve system capacity, allowing more patients to access cancer care	Short-term:  a. Enhance HA working hours via insourcing Long-term:  b. Relax the rules for admitting overseas doctors to practice in Hong Kong	Waiting time from diagnosis to treatment for all cancers
Access to Therapies	5	Improve patient access to therapies	Short-term:  a. Streamline the application process for subsidy b. Offer riders for VHIS cancer care specialty products c. Expand CCF coverage to the middle-income class and lower the threshold for subsidy application  Mid-term: d. Set up a separate Cancer Fund and use the interest e. Explore managed access agreements with pharmaceutical stakeholders to expedite patient access for innovative therapies which have already gained safety approval  Long-term: f. Offer tax deductions for people who self-pay for care/therapies at accredited institutions	<ul> <li>Approved subsidy applications via safety net schemes by population income</li> <li>Cases of under-reported income during application to safety net schemes</li> </ul>
Holistic Care	6	Move towards a holistic approach to cancer care that focuses on patient experience	Short-term:  a. Create a fully integrated patient portal for cancer information at all stages of the patient journey, centralising public, private and community resources, and including functionality to capture feedback on services, outcomes and patient experience  Long-term:  b. Expand the Cancer Case Manager (CCM) Programme to all cancer fields and adopt a Multidisciplinary Team (MDT) approach to cancer care	<ul> <li>Patient response to aspects of cancer care</li> <li>Percentage of patients having second or third-line therapy who have been enrolled in a CCM Programme</li> </ul>

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