

立法會
Legislative Council

LC Paper No. CB(2)190/17-18
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by the Administration)

Ref : CB2/PS/1/16

Panel on Welfare Services and Panel on Health Services

Joint Subcommittee on Long-term Care Policy

Minutes of the eighth meeting
held on Tuesday, 18 July 2017, at 10:45 am
in Conference Room 2 of the Legislative Council Complex

Members present : Dr Hon Fernando CHEUNG Chiu-hung (Chairman)
Hon SHIU Ka-chun (Deputy Chairman)
Hon LEUNG Yiu-chung
Prof Hon Joseph LEE Kok-long, SBS, JP
Hon CHAN Han-pan, JP
Hon Alvin YEUNG
Dr Hon Pierre CHAN
Hon KWONG Chun-yu

Public Officers attending : Item II

Mr Howard CHAN, JP
Deputy Secretary for Food and Health (Health)1

Miss Linda LEUNG
Principal Assistant Secretary for Food and Health
(Health) 2

Ms Ivis CHUNG
Chief Manager (Allied Health)
Hospital Authority

Ms Anna LEE
Chief Pharmacist
Hospital Authority

Attendance by invitation : Item II

DAB

Mr Pan YIP
Deputy Spokesperson of Policy

Liberal Party

Ms TSANG Cheuk-yi
Member

Labour Party

Mr KWOK Wing-kin
Vice-chairperson

Mr CHOY Kwong-sum

殘疾人士及長期病患者就業關注組

王芷欣小姐
秘書

林珍女士

Mr Ronald CHOW Kuen-tai

PNH 病人權益關注組

Dr CHUNG Chi-ho
成員

Hong Kong Alliance for Rare Diseases

Mr TSANG Kin-ping
President

Mr LAI Ka-wai

Ms LAM Sin-man

Hong Kong Alliance of Patients' Organizations
Limited

Mr YUEN Siu-lam
Chairman

胡就維先生

Adult blood cancer group

Miss Isabelle HO Kwan-ling
Chairperson

Ms CHONG Kiu-yun

Ms Carol LEUNG Shuk-man

Tuberous Sclerosis Complex Association of Hong
Kong

阮佩玲女士
Chairperson

Hong Kong Rett Syndrome Association

Ms Helen TSUI
Representative

League of Social Democrats

Mr LEUNG Kwok-hung
Representative

**Clerk in
attendance** : Mr Colin CHUI
Chief Council Secretary (2) 4

**Staff in
attendance** : Miss Kay CHU
Senior Council Secretary (2) 5

Miss Meisy KWOK
Legislative Assistant (2) 6

Action

I. Proposed continuation of work of the Joint Subcommittee

[LC Paper No. CB(2)1924/16-17(01)]

The Chairman said that according to the arrangements for the extension of period of work of policy subcommittees in the Sixth Legislative Council agreed by the House Committee ("HC") at its meeting on 7 July 2017, the Joint Subcommittee would cease its work upon completion of the 12-month period which would end in December 2017. After having taken into account the subject to be discussed at today's meeting, the Joint Subcommittee had already studied a total of seven subjects out of the 18 subjects identified for discussion since December 2016. It was envisaged that the three Joint Subcommittee meetings in October to December 2017 would be devoted to studying three of the 11 outstanding subjects and wrapping up its study and deliberation of its observations and recommendations. He suggested that the Joint Subcommittee should work beyond the 12-month period for studying the remaining eight subjects; and should therefore seek endorsement of the Panel on Welfare Services and Panel on Health Services as well as HC for the Joint Subcommittee to be put on the waiting list for re-activation. Members agreed.

II. Policy on subsidizing chronic patients for purchasing expensive drugs

[LC Paper Nos. CB(2)1885/16-17(01) to (13), CB(2)1896/16-17(01), CB(2)1932/16-17(01) to (02) and CB(2)1957/16-17(01) to (04)]

2. The Joint Subcommittee deliberated (index of proceedings attached at **Annex**).

III. Any other business

3. There being no other business, the meeting ended at 12:51 pm.

Council Business Division 2
Legislative Council Secretariat
31 October 2017

**Proceedings of the eighth meeting of the
Joint Subcommittee on Long-term Care Policy
on Tuesday, 18 July 2017, at 10:45 am
in Conference Room 2 of the Legislative Council Complex**

Time marker	Speaker(s)	Subject(s) / Discussion	Action required
<i>Agenda item I – Proposed continuation of work of the Joint Subcommittee</i>			
000549 – 000729	Chairman	Consent of members on the proposed continuation of work of the Joint Subcommittee	
<i>Agenda item II – Policy on subsidizing chronic patients for purchasing expensive drugs</i>			
000730 – 001120	Chairman	Opening remarks	
001121 – 001422	DAB	Presentation of views	
001423 – 001743	Liberal Party	Presentation of views	
001744 – 002056	Labour Party	Presentation of views [LC Paper No. CB(2)1957/16-17(01)]	
002057 – 002442	Mr CHOY Kwong-sum	Presentation of views	
002443 – 002734	殘疾人士及長期病患者就業關注組	Presentation of views [LC Paper No. CB(2)1885/16-17(05)]	
002735 – 002956	林珍女士	Presentation of views	
002957 – 003249	Mr Ronald CHOW Kuen-tai	Presentation of views	
003250 – 003558	PNH 病人權益關注組	Presentation of views [LC Paper No. CB(2)1885/16-17(03)]	
003559 – 003857	Hong Kong Alliance for Rare Diseases	Presentation of views [LC Paper No. CB(2)1885/16-17(04)]	
003858 – 004145	Mr LAI Ka-wai	Presentation of views	
004146 – 004502	Ms LAM Sin-man	Presentation of views	
004503 – 004836	Hong Kong Alliance of Patients' Organizations Limited	Presentation of views [LC Paper No. CB(2)1885/16-17(06)]	

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004837 – 005156	胡就維先生	Presentation of views [LC Paper No. CB(2)1957/16-17(02)]	
005157 – 005209	Adult blood cancer group	Presentation of views	
005210 – 005559	Ms CHONG Kiu-yun	Presentation of views	
005600 – 010000	Ms Carol LEUNG Shuk-man	Presentation of views	
010001 – 010316	Tuberous Sclerosis Complex Association of Hong Kong	Presentation of views	
010317 – 010544	Hong Kong Rett Syndrome Association	Presentation of views	
010545 – 010959	League of Social Democrats	Presentation of views	
011000 – 012605	Chairman Admin Hospital Authority ("HA")	<p>The Chairman invited the Administration to respond to the views expressed and suggestions made by the deputations and individuals on the policy on subsidizing chronic patients for purchasing expensive drugs, including but not limited to the low transparency and inefficiency as well as lack of patients' participation in the introduction of new drugs into the Drug Formulary of HA ("HADF"); high thresholds for the drug subsidies programmes under Samaritan Fund ("SF") and Community Care Fund ("CCF"); and inadequacies in the use of drugs for treatment of uncommon disorders such as Tuberous Sclerosis Complex ("TSC") and Spinal Muscular Atrophy ("SMA"). He was particularly concerned that some patients in need of expensive drugs claimed to be denied adequate medical treatment due to lack of means, which ran counter to the Government's public healthcare policy.</p> <p>The Administration gave a succinct brief on the Government's public healthcare policy, the implementation of HADF and provision of subsidy for eligible patients for the expenses on self-financed drugs under SF and the exiting and impending CCF Medical Assistance Programmes, details of which were set out in paragraphs 2 to 4, 6 and 8 to 9 of the Administration's paper [LC Paper No. CB(2)1885/16-17(01)] and added that:</p>	

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		<p>(a) a new CCF Medical Assistance Programme would be launched to subsidize eligible patients to purchase ultra-expensive drugs, under which the patient's maximum contribution to drug expenses was set at 20% of the patient's annual disposable household financial resources by making reference to that of SF, plus an annual maximum contribution which was capped at \$1 million. Having regard to some patient groups' calls for further relaxing the said criteria, the Administration would review the financial assessment criteria of drug subsidies programmes under CCF and SF in one go ("the Review"). In the meantime, the Administration would implement the new CCF Medical Assistance Programme in August 2017 to enable early use of ultra-expensive drugs by needy patients;</p> <p>(b) the Administration would continue to examine the feasibility of enhancing the implementation of SF and the CCF Medical Assistance Programmes. In addition, it would discuss with HA to examine how to enhance the existing mechanism for introducing new drugs into HADF; and</p> <p>(c) a written reply to the views expressed and suggestions made by the deputations and individuals would be provided after the meeting.</p> <p>HA briefed members on the development of SF set out in paragraphs 12, 13 and 15 of the Administration's paper [LC Paper No. CB(2)1885/16-17(01)] and added that:</p> <p>(a) with the treatment protocol for TSC with renal angiomyolipoma recently formulated by the relevant multidisciplinary expert panel, HA planned to extend the coverage of SF to the said disease under the established mechanism within the current financial year. By making reference to relevant overseas practices, it was proposed that one of the eligibility criteria for the said subsidy under SF was that the size of the benign tumor(s) of an applicant should be at least 3cm. HA also targeted to extend the coverage of the new CCF Medical Assistance</p>	

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		<p>Programme for ultra-expensive drugs to eligible patients with Atypical hemolytic uremic syndrome ("aHUS") within the current financial year; and</p> <p>(b) HA aimed to complete the Review in early 2018, and would revert to the Joint Subcommittee on the outcome of the Review as and when appropriate.</p> <p>The Chairman expressed concern about inadequacies in the existing financial assessment criteria of drug subsidies programmes under CCF and SF, in particular the definition of "household" which included the patient and his/her spouse, children, parents and dependent siblings, where applicable, and the inclusion of pension and provident fund in the monthly household gross income. He called on the Administration to relax the criteria in order to benefit more needy patients.</p>	
012606 – 013441	Chairman Mr LEUNG Yiu-chung Admin HA	<p>Mr LEUNG Yiu-chung expressed disappointment that the Administration did not take concrete steps to ensure that no one was denied adequate medical treatment due to lack of means. Noting that some needy patients could not benefit from the drug subsidies programmes under CCF and SF, he urged the Administration and HA to expedite the Review, and extend the coverage of SF and CCF to eligible patients suffered from TSC with renal angiomyolipoma or aHUS without further delay.</p> <p>The Administration advised that at its recent meeting with patient group and representatives, the Administration had explained that various measures would be taken to strengthen the support for patients with different illness and conditions. Specifically, the Administration would implement the new CCF Medical Assistance Programme to subsidize eligible patients to purchase ultra-expensive drugs and continue to liaise with pharmaceutical companies in providing appropriate support for individual patients. HA reiterated that the Review was expected to be completed in early 2018 taking into account the time required to collect statistics in respect of the new CCF Medical Assistance Programme to be launched in August 2017.</p>	

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		<p>Mr LEUNG Yiu-chung was discontent that he wrote to HA and the Department of Health ("DH") several times last year to try to line up meetings with representatives of patients with uncommon disorders, HA and DH. But no positive response had been received from the latter two so far. The Chairman urged the Administration and HA to follow up in this regard after the meeting.</p>	
<p>013442 – 014403</p>	<p>Chairman Mr KWONG Chun-yu Admin HA</p>	<p>Mr KWONG Chun-yu expressed grave concern that some patients with uncommon disorders had their assets depleted for expenses on ultra-expensive drugs even with the support of drug subsidies and some of those with SMA encountered difficulties in obtaining unregistered drugs for treatment. He strongly urged the Administration to conduct a comprehensive review of the policy on uncommon disorders and the implementation of HADF without further delay, and consider submitting a funding proposal to subsidize patients with uncommon disorders for their drug expenses for consideration by the Finance Committee of the Legislative Council. He further invited the Secretary for Food and Health, representatives from the Administration and HA to have a meeting in August 2017 with stakeholders and him to discuss issues relating to uncommon disorders.</p> <p>The Administration advised that it welcomed exchanges with members and stakeholders on issues relating to uncommon disorders. It stressed that the implementation of the new CCF Medical Assistance Programme would be a breakthrough to provide eligible patients with subsidy to purchase ultra-expensive drugs which had not yet been introduced into HADF. The Administration took note of some deputations' views on the thresholds for the drug subsidies programmes under CCF and SF.</p> <p>HA advised that it would apply for a required license from DH for importing an unregistered drug for the purpose of treatment of a particular patient if a public doctor made the relevant application and the pharmaceutical company concerned agreed and was able to export the drug to Hong Kong. It should be noted that HADF currently included, among others, over 200</p>	

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		<p>unregistered drugs for prescription by public doctors to patients subject to their clinical conditions. Regarding the calls for early importation of the drug namely Spinraza for treatment of SMA, HA advised that the drug, which was first registered in the United States of America in December 2016, had not yet been decided by the pharmaceutical company concerned on when to be exported to Hong Kong for sale at this stage. HA would keep in view the development in this regard.</p>	
014404 – 015359	<p>Chairman Deputy Chairman Admin HA</p>	<p>Noting that the Review was expected to take a year to complete, the Deputy Chairman questioned about the number of meetings would be held and whether stakeholders including patients and their family members would participate in the process. He further urged the Administration and HA to benefit more needy patients from drug subsidies by allowing patients to apply on an individual basis, expedite the vetting of the applications and relax the financial assessment criteria by disregarding annual disposable household financial resources and taking into account income and employment status of the applicants. In addition, he also asked about how cost-effectiveness was measured in evaluating new drug applications for listing on HADF.</p> <p>HA reiterated that the Review was expected to be completed in early 2018 taking account of the time required to collect statistics in respect of the new CCF Medical Assistance Programme to be launched in August 2017. HA would engage a consultant to conduct the Review which would focus on reviewing the financial assessment criteria of drug subsidies programmes under CCF and SF.</p> <p>The Chairman called on the Administration and HA to listen to the views expressed by stakeholders, including patient groups, patients and their family members. HA took note of stakeholders' views.</p>	
015400 – 020502	<p>Chairman Ms LAM Sin-man 殘疾人士及長期病患者就業關注組</p>	<p>At the invitation of the Chairman, some deputations and individuals gave further views on better utilizing ultra-expensive drugs for treatment of patients with uncommon disorders such as</p>	

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	<p>林珍女士 Tuberous Sclerosis Complex Association of Hong Kong 胡就維先生 League of Social Democrats Admin HA</p>	<p>those suffered from TSC, lowering the high thresholds and expediting vetting process of applications for drug subsidies, allocating more resources to enhance the provision of social welfare and healthcare services for chronic patients, ensuring no one would be denied adequate medical treatment due to lack of means and maintaining close liaison among the Administration, HA and stakeholders.</p> <p>The Administration advised that it would discuss with HA to examine how to better collate stakeholders' views during the course of the Review by the consultant to be engaged by HA. HA assured members that stakeholders' views would be taken into account in the Review, and some deputations' views on the use of drugs for treatment of TSC would be referred to the relevant independent expert panel of HA for consideration.</p>	
020503 – 021035	Chairman	<p>The Chairman said that he and other members would follow up the deputations' views and suggestions with the Administration and HA after the meeting. He also called on the Administration and HA to:</p> <ul style="list-style-type: none"> (a) strengthen their efforts in discussing with relevant pharmaceutical companies to lower drug prices, in particular those of ultra-expensive drugs; (b) expedite the extension of drug subsidies programmes to more new drugs and relax the eligibility criteria of these programmes in order to benefit more needy patients; and (c) expedite the Review and require the consultant to be engaged by HA to take into account stakeholders' views in this regard, including those expressed at this meeting. 	