立法會
Legislative Council

LC Paper No. CB(2)2737/07-08
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Panel on Health Services

Minutes of special meeting
held on Tuesday, 24 June 2008, at 4:30 pm
in the Chamber of the Legislative Council Building

Members present	:	Dr Hon Joseph LEE Kok-long, JP (Deputy Chairman) Hon Fred LI Wah-ming, JP Hon CHAN Yuen-han, SBS, JP Hon Mrs Sophie LEUNG LAU Yau-fun, GBS, JP Dr Hon YEUNG Sum, JP Hon Andrew CHENG Kar-foo Hon Audrey EU Yuet-mee, SC, JP Hon LEUNG Kwok-hung Dr Hon KWOK Ka-ki Dr Hon Fernando CHEUNG Chiu-hung
Member attending	:	Hon SIN Chung-kai, SBS, JP
Members absent	:	Hon LI Kwok-ying, MH, JP (Chairman) Hon Mrs Selina CHOW LIANG Shuk-yee, GBS, JP Hon Vincent FANG Kang, JP
Public Officers attending	:	Item I Miss Gloria LO Principal Assistant Secretary for Food and Health (Health)

Dr W L CHEUNG, JP
Director (Cluster Services)
Hospital Authority

Dr Beatrice CHENG
Chief Manager (Cluster Performance)
Hospital Authority

Mr LEE Pak-wai
Chief Pharmacist
Hospital Authority

Ms LEE See-wing
Senior Pharmacist
Hospital Authority

Item II

Mrs Ingrid YEUNG
Deputy Secretary for Food and Health (Health)2

Mr Thomas CHAN
Deputy Secretary for Food and Health (Health) Projects

Attendance by invitation : Thalassaemia Association of Hong Kong

Mr LEUNG Ka-fai
Chairman

Mr HO Tse-hin
Patient Representative

Miss HO Sze-nga
Patient Representative

Miss YEUNG Sheung-yu
Patient Representative

Miss CHUNG Hei-tung
Patient Representative

Children's Thalassaemia Foundation

Ms WONG Hang-yue
Director

Ms SIU King-lan

Dr HA Shau-yin
Consultant, Department of Paediatrics and Adolescent Medicine, Queen Mary Hospital

Clerk in attendance : Miss Mary SO
Chief Council Secretary (2) 5

Staff in attendance : Ms Amy YU
Senior Council Secretary (2) 3

Ms Sandy HAU
Legislative Assistant (2) 5

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I. Iron chelating therapy for Thalassaemia patients in public hospitals
(LC Paper Nos. CB(2)2377/07-08(01), CB(2)1967/07-08(01) and CB(2)2388/07-08(01) to (02))

Director (Cluster Services), Hospital Authority (HA) and Chief Manager (Cluster Performance), HA briefed members on the iron chelating therapy for Thalassaemia patients provided by public hospitals (LC Paper No. CB(2)2377/07-08(01)) with the aid of a power-point.

Views of deputations/individual

Thalassaemia Association of Hong Kong

2. With the aid of a video presentation, Miss CHUNG Hei-tung introduced the submission of the Thalassaemia Association of Hong Kong [LC Paper No. CB(2)2388/07-08(01)] which urged HA to include Deferasirox (also known as Exjade) as a General Drug in the HA Drug Formulary (the Formulary). There were currently three iron chelating agents, namely, Desferrioxamine (DFO), Deferiprone and Exjade, available in HA for removing the excessive iron accumulated in the bodies of Thalassaemia patients due to regular blood

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transfusions. DFO, classified as a General Drug and used as a first-line treatment in HA hospitals, was administered by a subcutaneous transfusion taking eight to 12 hours each day to be provided to a patient five to seven times a week. The Association pointed out that this time-consuming, painful regimen and its side effects, such as bone deformity, and scarring, swelling and hardening of the skin at the injection site, had caused much sufferings to the patients rendering them unable to lead normal and productive lives. As for Deferiprone, an oral medication used by HA as a second-line treatment for patients for whom DFO therapy was contraindicted, intolerant or non-compliant, the Association pointed out that despite its effectiveness for some patients, its side effects of severe joint pain, agranulocytosis and neutropenia made it unsuitable for many patients. According to the Association, Exjade, a new oral iron removal drug, caused comparatively minor side effects and its clinical efficacy was comparable to DFO. However, it was currently classified as a self-financed drug and its high cost made it inaccessible to many patients. The Association therefore urged HA to include Exjade as a General Drug in the Formulary so that it would be provided to patients within the standard fees and charges.

Children's Thalassaemia Foundation

3. Ms WONG Hang-yue and Ms SIU King-lan recounted the sufferings experienced by their children who were Thalassaemia patients when undergoing the DFO therapy. They urged HA to include Exjade as a General Drug in the Formulary to help enhance the quality of life of Thalassaemia patients, as some patients taking Deferiprone suffered severe complication of agranulcytosis.

Dr HA Shau-yin, Consultant, Department of Paediatrics and Adolescent Medicine, Queen Mary Hospital

4. Dr HA Shau-yin introduced his submission [LC Paper No. CB(2)2388/07-08(02)] setting out a comparison of the various iron chelating agents. He pointed out that whilst DFO had a long history of use and major side effects were uncommon, its cumbersome and demanding administering process resulted in poor patient compliance, particularly when patients reached adolescence and adulthood. As for Deferiprone, there was a significant risk of neutropenia and agranulcytosis, mandating weekly blood monitoring. Dr HA further pointed out that Exjade was recommended as a first- and second-line treatment by the International Thalassaemia Federation and the Italian Society of Hematology respectively. Nevertheless, considering that Exjade was a relatively new drug and its side-effects were not well-established, he considered that Exjade should be used only in urgent indications for patients who could not use Deferiprone as a second-line drug due to severe complications.

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5. Members also noted the submission from Hind Wing Co. Ltd. (LC Paper No. CB(2)2431/07-08(01)) tabled at the meeting.

Discussion

6. Dr Fernando CHEUNG said that as pointed out by the deputations, for some Thalassaemia patients, the existing first- (i.e. DFO) and second-line iron chelating agents (i.e. Deferiprone or a combination of DFO and Deferiprone) provided by HA had failed to achieve adequate chelation and/or had caused serious side effects. For these patients, Exjade offered an additional choice of second-line treatment. Whilst Exjade was a new drug and there was a consequent lack of evidential support on its long-term efficacy and safety, it was noteworthy that it had been approved for marketing in the United States (US) by the US Food and Drug Administration (FDA) and there was also preliminary medical evidence on its clinical efficacy. As Exjade was currently classified as a self-financed item, its high cost (about $20,000 per month) had rendered it unaffordable to many patients. Noting from the Annex to the Administration's paper that 52.9% of Exjade-treated patients had responded to the treatment as compared with 66.4% for DFO, Dr CHEUNG said that such figures showed that Exjade was a drug of significant, rather than marginal, benefits and as such should not be classified as a self-financed item. Having regard to the Administration's long-standing policy that no patient would be denied adequate medical treatment due to lack of means as well as the small and declining number of Thalassaemia patients in Hong Kong, Dr CHEUNG asked whether consideration would be given to including Exjade in the Formulary as a second-line drug to be provided in cases where it had been clinically assessed by the attending doctors that the drug should be prescribed for patients for appropriate treatment. Dr YEUNG Sum raised a similar question.

7. Director (Cluster Services), HA responded that when considering the inclusion of a drug into the Formulary, HA was guided by the principles of clinical efficacy, safety, cost-effectiveness, opportunity cost as well as facilitation of patients' choice. Both DFO and Deferiprone were currently covered by HA's highly subsidized scope of standard treatment. DFO was classified as a General Drug while the oral drug Deferiprone was available as a Special Drug. DFO had been in the market for more than 40 years and was proven to be clinically effective with rare incidence of severe complications. Should the DFO therapy be contraindicated, intolerant or non-compliant, Deferiprone, which had been in the market for almost nine years and its side effects were relatively well-established, would be used as the standard second-line treatment. As far as Exjade was concerned, the drug was of preliminary medical evidence only and was currently available as a self-financed item. As Exjade was put to market only in November 2005, evidence on its long-term benefits and risks was lacking. Furthermore, there were also reports of possible severe side effects and fatal complications in

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using Exjade. The figures cited by Dr Fernando CHEUNG in paragraph 6 above also indicated that it was less effective than DFO. In view of the aforesaid considerations, HA considered it necessary to continue to monitor the effects of Exjade for a further period of time before reviewing its positioning in the Formulary.

8. Director (Cluster Services), HA further said that he was aware of the concern of Thalassaemia patients about the possible side effect of agranulocytosis on using Deferiprone. He however pointed that such risk was very low (1.1%). In most cases, DFO and Deferiprone should be sufficient to meet the needs of the great majority of Thalassaemia patients. For those exceptional cases where DFO had failed to achieve adequate chelation and the use of Deferiprone had caused serious complications, they could be dealt with on a case-by-case basis. Under such mechanism, an expert panel would be responsible for approving, monitoring, recording and tracking such prescriptions.

9. In the light of HA's response on the efficacy and side effects of Exjade given in paragraph 7 above, Dr YEUNG Sum sought an elaboration from Dr HA Shau-yin on the basis for his view that it should be used as a second-line treatment in HA hospitals.

10. Dr HA Shau-yin responded that Exjade had been shown to be comparable to DFO in terms of clinical efficacy. Dr HA further pointed out that according to the article in US FDA's Drug Safety Newsletter on cases of suspected adverse drug reactions in association with the use of Exjade, some of the patients who had suffered adverse reactions had other pre-existing diseases and the contributory role for Exjade was unclear in some cases. Taking into account the benefits and risks of Exjade vis-à-vis those of DFO and Deferiprone, he was of the view that the drug should be used as a second-line treatment in cases where DFO had failed to achieve adequate chelation and the use of Deferiprone had caused severe complications.

11. The Deputy Chairman sought clarification on whether Deferiprone was indeed an unregistered drug as alleged by some patient organisations.

12. Director (Cluster Services), HA said that there was no cause for concern about the safety of Deferiprone. Deferiprone, like all other drugs in the Formulary, had been registered in Hong Kong. In US, Deferiprone had been granted the "orphan drug" status (i.e. drugs for rare disorders) by the FDA and had received market authorization in US. In addition, Deferiprone was also a registered drug in many advanced countries such as the United Kingdom and Australia.

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13. Miss CHAN Yuen-han said that the special mechanism mentioned by Director (Cluster Services), HA in paragraph 8 above should not involve cumbersome administrative procedures; otherwise doctors would be deterred from using it. She further sought clarification on whether the approval of senior doctors at the rank of, say, Consultant was required for the prescription of Exjade under such mechanism.

14. Director (Cluster Services), HA clarified that under the special mechanism for dealing with the exceptional cases mentioned in paragraph 8 above, the attending doctors might refer the cases to an expert panel for consideration of approval for the prescription of Exjade. Director (Cluster Services), HA stressed that as Exjade was a new drug and its side effects had not been fully established, it would be more appropriate for the decision on prescription of the drug to be made by an expert panel rather than solely by the attending doctor. At the request of Miss CHAN, Director (Cluster Services), HA undertook to disseminate information and guidelines on the mechanism to doctors in all the seven hospital clusters as soon as practicable.

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15. Dr KWOK Ka-ki was of the view that the decision on prescription of Exjade should best be left to the attending doctor, rather than to an expert panel. He considered such arrangement unacceptable as it was an encroachment on the clinical judgment and professional autonomy of individual doctors. Dr KWOK further said that due to financial constraints, HA was not able to provide all its patients with the drugs they required. He urged the Administration to increase its funding allocation to HA to ensure that all patients would be given equitable access to effective drug therapy.

16. Miss HO Sze-nga of the Thalassaemia Association of Hong Kong said that she was one of the small number of patients who suffered from neutropenia on taking Deferiprone. In her case, DFO had failed to achieve adequate chelation but the taking of Deferiprone would cause the occurrence of neutropenia. The high cost of Exjade was unaffordable to her. Miss HO was glad to learn that there was a special mechanism for providing patients with Exjade at highly subsidized rate and would contact her attending doctor about it in no time.

17. Dr YEUNG Sum said that life was priceless and urged HA to include Exjade in the Formulary to provide Thalassaemia patients with an additional option of iron chelating therapy. He however stressed that as the drug was new, it was important to ensure that its prescription was based on patients' clinical indications and guided by clear clinical protocols.

18. Dr Fernando CHEUNG reiterated his view that Exjade should not be classified as a self-financed drug item as it was not a drug of only marginal benefits.

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19. Director (Cluster Services), HA explained that the major consideration for classifying Exjade as a self-financed item was that it was a drug of preliminary medical evidence only. He reiterated that the drug had been in the market for only a short period of time and there was a need to further monitor its therapeutic effectiveness and safety. In the meantime, a special mechanism would be in place for handling those exceptional cases where both DFO and Deferiprone had failed to provide effective treatment. Apart from ensuring proper medical standard, the mechanism would also help to centralize the relevant clinical expertise and experience. At the request of Dr Fernando CHEUNG and the Deputy Chairman, Director (Cluster Services), HA agreed to provide information in writing on the operation of the mechanism after the meeting.

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Conclusion

20. Dr Fernando CHEUNG proposed to move the following motion -

"鑒於爲地中海貧血病患者提供的排鐵療法及藥物有新進展，本委員會促請醫院管理局(“醫管局”)將已被證實具療效作用的地拉羅司列作經醫生推薦藥物，放於藥物名冊內，讓醫生根據病人個別情況，在有需要時可以應用，以達治療之效果。政府亦應因應需要而增加對醫管局的撥款。"

(Translation)

"That, in view of the new development in iron chelating therapy and medication for Thalassaemia patients, this Panel urges the Hospital Authority (HA) to include Deferasirox (Exjade), which has proven efficacy, in the Drug Formulary, so that doctors can, based on individual patients' conditions, prescribe the drug when necessary to achieve curative effect; and that the Government should also increase funding to HA as required."

21. The Deputy Chairman put the motion to vote. All members present voted in favour of the motion. The Deputy Chairman declared that the motion was carried.

II. Consultation on Healthcare Reform

(LC Paper No. CB(2)2388/07-08(03))

22. The Deputy Chairman informed members that the Secretary for Food and Health (SFH) sent his apologies for not being able to attend the meeting due to other urgent official business.

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23. Deputy Secretary for Food and Health (Health)2 (DSFH((H)2) briefed members on the progress of the consultation on healthcare reform. DSFH((H)2 said that at the conclusion of the first stage of the public consultation on the Healthcare Reform Consultation Document entitled "Your Health, Your Life" (Consultation Document) ending on 13 June 2008, more than 4 300 submissions from individuals and organisations had been received. These included 3 200 standard forms, 100 submissions from organizations and 1 000 submissions from individuals. During the three-month consultation period, officials of the Food and Health Bureau had attended more than 150 forums organized by different sectors. A survey by questionnaire and focus group discussions were underway to collect more public opinion and views. The Administration would take into account the views expressed by different sectors of the community when devising more concrete proposals for second stage consultation aimed to take place in the first half of 2009. DSFH((H)2 further said that the first stage consultation revealed that the public generally supported the four major service reform proposals put forth in the Consultation Document, viz. enhancing primary care, promoting public-private partnership in healthcare, developing electronic health record sharing and strengthening public healthcare safety net, and the Administration would actively take forward the reform proposals.

24. Referring to the survey on supplementary healthcare financing conducted by the Public Opinion Programme of the University of Hong Kong in May 2008 (LC Paper No. CB(2)2388/07-08(03)) which was commissioned by him, Dr KWOK Ka-ki said that the results of the survey indicated that only 3.4% of the respondents had a fairly good or good grasp of the six supplementary financing options put forward in the Consultation Document, while 78.1% did not know much about them. Given that the public were not fully informed on the six options and there had been no specific details for them to discuss, Dr KWOK queried the basis for the Administration coming up with further proposals on supplementary financing in the next stage of the consultation. Miss CHAN Yuen-han echoed similar views. Dr KWOK further said that many sources indicated that the public generally held a strong view against mandatory schemes such as mandatory private health insurance. He asked whether the Administration had taken any position on the financing options.

25. DSFH((H)2 responded that the Administration was aware of the view that there were not sufficient details about the six supplementary financing options proposed in the Consultation Document. Given that healthcare reform was a highly complex issue, the consultation was thus launched in two stages. In the first stage, the Administration intended to kick-start discussions by consulting the public on the concepts of the healthcare reforms as well as the advantages and disadvantages of various financing options. Detailed proposals, including those of supplementary financing arrangements, for the second stage consultation would

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be formulated on the basis of views received during the first stage consultation. Deputy Secretary for Food and Health (Health) Projects supplemented that the public had expressed mixed views on the six financing options, each of which had its own pros and cons, and the choice between the options was very much a choice of the community reflecting its societal values on matters such as risk pooling and wealth re-distribution. The Administration had yet to form any views on the financing options and would carefully consider the public's views and preference when drawing up concrete proposals for the next stage of the consultation.

26. Miss CHAN Yuen-han said that many members of the public took the view that the Administration should implement the service reforms proposed in the Consultation Document to improve the shortcomings of the present healthcare system before asking the public for more money to finance healthcare expenditure. Mr LEUNG Kwok-hung expressed similar views, saying that the service reform proposals set out in the Consultation Document should not be bundled together with the proposals on supplementary financing. In his view, the Administration should also work out ways to address the shortcomings of the present healthcare system under the assumption that no supplementary financing would be introduced.

27. DSFH((H)2 responded that as she had mentioned earlier at the meeting, the Administration recognized that there was consensus in the community on taking forward the service reform proposals and would start work in this regard. The Chief Executive (CE) had pledged to increase expenditure on public healthcare from 15% to 17% of recurrent government expenditure by 2011-2012. It was envisaged that these additional resources would be able to cope with the growth in service needs in the coming few years, as well as to conduct preparatory works for healthcare service reforms, so as to improve existing services within possible scope before putting in place any supplementary financing arrangements. However, in face of an ageing population and rising medical costs, it was incumbent upon the Administration to plan for the long-term sustainability of the healthcare system beyond the next couple of years. It was necessary to reform the current healthcare financing arrangements alongside the service reforms to provide a steady and sustainable source of supplementary funding to fully carry out and sustain the service reform initiatives.

28. In response to Miss CHAN Yuen-han's request for a timetable for the implementation of the service reform proposals, DSFH((H)2 said that it would be difficult to provide such at the present stage. Given the differences in the amount of planning and preparation work involved, the four major reform proposals would inevitably progress at different paces. Nevertheless, DSFH((H)2 assured members that the Administration would take forward the service reforms as soon as practicable. In fact, preparation work for some of the reform proposals had already started. For instance, planning for the development of an electronic

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platform for sharing of health record and various pilot projects for enhancing primary care and promoting public-private partnership in healthcare were underway. DSFH((H)2 further undertook to report to the Panel the progress on taking forward the reform initiatives at appropriate junctures in the future.

29. Dr KWOK Ka-ki asked whether consideration would be given to immediately releasing the $50 billion from the fiscal reserve pledged by the Financial Secretary (FS) to set up a fund for implementing the healthcare reform proposals, having regard to the general consensus in the community on taking forward the service reform proposals.

30. DSFH((H)2 reiterated that in the process of developing the future healthcare system, the Government's commitment to public healthcare would only be increased and not reduced, as demonstrated by CE's pledge to increase the government expenditure on healthcare from 15% to 17% of recurrent government expenditure. It was estimated that by 2011-2012, the annual recurrent health expenditure would increase by about $10 billion. With these additional resources, the Administration believed that the quality of healthcare services would be greatly enhanced in the coming few years. DSFH((H)2 further pointed out that in addition to availability of financial resources, manpower supply was also a crucial factor in determining the pace of the healthcare reform. Even if the $50 billion pledged by FS was immediately released for implementing the reform initiatives, there would not be an adequate supply of healthcare professionals to provide all the enhanced services. As manpower resources could not be made available overnight, the reform proposals had to be implemented in a progressive manner to ensure that both the software and hardware of the healthcare system could cope with the enhanced services.

31. Miss CHAN Yuen-han pointed out that some Chinese medicine practitioners (CMPs) had expressed concern that the Consultation Document was silent on the role of CMPs in the healthcare reform. DSFH((H)2 said that no particular mention was made on the role of CMPs in the Consultation Document because CMPs, like western medicine doctors, were very much an integral part of the healthcare system, as reflected in the case of the elderly healthcare voucher pilot scheme, whereby the healthcare vouchers could be used for purchasing services provided by western medicine doctors as well as CMPs.

32. Dr Fernando CHEUNG expressed disappointment with the Administration's failure to shed any light at the meeting on major views received during the consultation exercise and how those views would impact on the direction for future work. It appeared that the Administration had winded up the first stage of the consultation in a perfunctory manner, which was regrettable considering the importance of the healthcare reform and its far-reaching implications.

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33. DSFH((H)2 responded that there was no question of the Administration winding up the first stage consultation in a perfunctory manner. Given that the first stage consultation had just ended about 10 days ago and more than 4 300 submissions had been received, it would take time to collate and analyze the views received. Upon completion of such analysis, the Administration would formulate detailed proposals for the second stage consultation to address the issues and concerns raised by the public, such as the role of the Government and employers in making contributions to supplementary financing and what kind of healthcare protection the public could get by contributing to a financing option. She assured members that detailed proposals on the reform and the basis thereof would be made available for public discussion when the second stage consultation was launched in the first half of 2009.

34. The Deputy Chairman asked whether the Administration would provide a summary of the views received during the first stage consultation to the Panel before the launch of the second stage consultation, say in October or November 2008. DSFH((H)2 responded that it was the Administration's plan to provide such information to the Panel, as in the case of the consultation document entitled "Building a Healthy Tomorrow" released in July 2005. It was expected that such information would be provided to the Panel in around end of 2008 or early 2009 upon completion of the analysis on views received during the consultation period.

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35. Dr KWOK Ka-ki and Mr LEUNG Kwok-hung said that the Administration should not place the burden of providing supplementary healthcare financing on the working population. They criticized the Administration for reducing the tax burden of the wealthy through the lowering of the corporate profits tax rate and the standard rate of salaries tax, the waiving of the hotel accommodation tax and the exemption of duties on wine, beer and all other alcoholic beverages (except spirits) in the 2008-2009 Budget on the one hand, and asking the working population to contribute a certain percentage of their income to fund healthcare expenditure on the other. Mr LEUNG Kwok-hung further said that the Administration should reform the wage structure to enable the low-income groups to make contributions to supplementary healthcare financing before introducing any supplementary financing arrangements.

36. Dr KWOK Ka-ki suggested and members agreed to schedule a special meeting before the expiry of the current legislative term to further discuss consultation on healthcare reform and invite SFH to attend the meeting.

(*Post-meeting note*: The special meeting was scheduled for 7 July 2008 at 10:45 am.)

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37. There being no other business, the meeting ended at 6:33 pm.

Council Business Division 2
Legislative Council Secretariat
26 August 2008