Comment

A 30-year case study of local implementation of global guidelines for data-driven diabetes management starting with the Hong Kong Diabetes Register

Juliana C. N. Chan,[a,b,c,d,] Michael Cheung,[e] Andrea O. Y. Luk,[a,c] Harriet Chung,[f] Kit Man Loo,[g] Maria Kwan Wa Leung,[h] Kai-Ming Chow,[a,i] Juliana N. M. Lui,[a] Martin C. S. Wong,[j,k,l,m] Kin Lai Chung,[n] Maggie Lee,[o] Cheuk Chun Szeto,[a,i] Man Wo Tsang,[p] Sunny Wong,[p] Jack Kit Chung Ng,[a,d,i] Sydney C. W. Tang,[q] Kenny Kung,[r] Sing Leung Lui,[s] David V. K. Chao,[t] Coral Cyzewski,[e] Tanya Green,[e] Victor Hin-Fai Hung,[u] Fei Chau Pang,[v] and Philip Kam-Tao Li[a,i,w,**]*

[a]Department of Medicine and Therapeutics, The Chinese University of Hong Kong, Prince of Wales Hospital, Hong Kong Special Administrative Region of China
[b]Asia Diabetes Foundation, Shatin, Hong Kong Special Administrative Region of China
[c]Hong Kong Institute of Diabetes and Obesity, The Chinese University of Hong Kong, Prince of Wales Hospital, Hong Kong Special Administrative Region of China
[d]Li Ka Shing Institute of Health Sciences, The Chinese University of Hong Kong, Prince of Wales Hospital, Hong Kong Special Administrative Region of China
[e]KDIGO, Brussels, Belgium
[f]Shumshuipo District Health Centre, Hong Kong Special Administrative Region of China
[g]Diabetes & Endocrine Centre, Day Treatment Block and Children Wards, Prince of Wales Hospital, Hong Kong Special Administrative Region of China
[h]Department of Family Medicine & Primary Health Care, New Territories East Cluster, Hospital Authority, Hong Kong Special Administrative Region of China
[i]Carol and Richard Yu Peritoneal Dialysis Research Centre, Department of Medicine and Therapeutics, The Chinese University of Hong Kong, Hong Kong Special Administrative Region of China
[j]Centre for Health Education and Health Promotion, Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong, Hong Kong Special Administrative Region of China
[k]School of Public Health, Peking University, Beijing, China
[l]The Chinese Academy of Medical Sciences and Peking Union Medical College, Beijing, China
[m]School of Public Health, Fudan University, Shanghai, China
[n]Prince of Wales Hospital, New Territories East Cluster, Hong Kong Special Administrative Region of China
[o]Department of Medicine & Geriatrics, New Territories West Cluster, Hospital Authority, Hong Kong Special Administrative Region of China
[p]Department of Medicine and Geriatrics, United Christian Hospital, Hong Kong Special Administrative Region of China
[q]Division of Nephrology, Department of Medicine, School of Clinical Medicine, The University of Hong Kong, Hong Kong Special Administrative Region of China
[r]The GBA Healthcare Group, Hong Kong Special Administrative Region of China
[s]Department of Medicine, Tung Wah Hospital, Hong Kong Special Administrative Region of China
[t]Department of Family Medicine and Primary Health Care, United Christian Hospital, Hong Kong Special Administrative Region of China
[u]Department of Medicine and Geriatrics, Princess Margaret Hospital, Hong Kong Special Administrative Region of China
[v]Primary Healthcare Office, Health Bureau, Hong Kong Special Administrative Region of China
[w]International Association of Chinese Nephrologists, Shatin, Hong Kong Special Administrative Region of China

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Diabetes and its complications, notably chronic kidney disease (CKD) are silent disease states whose risk factors and treatment targets are often characterized by numerical values, thus making regular measurements imperative in guiding medical decisions and empowering patient self-management. In 2019, we summarized the evolution of the Hong Kong Diabetes Register (HKDR) established in 1995[1] into the platform-based Joint Asia Diabetes Evaluation (JADE) Programme in 2007[2] and a territory-wide Risk Assessment and Management Programme (RAMP) in 2009.[3] During this care transformation, we demonstrated how systematic gathering of personalized data can inform decisions at all levels including patients, providers and payors aimed at closing the gaps in prevention, care, data and professional knowledge.[4] In this commentary, we reported the continuing impacts of this data-driven integrated care model triggered by a diabetes register as first advocated by the St. Vincent Declaration of the

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*Corresponding author. Department of Medicine and Therapeutics, Hong Kong Institute of Diabetes and Obesity, Prince of Wales Hospital, The Chinese University of Hong Kong, Shatin, New Territories, Hong Kong Special Administrative Region of China.

**Corresponding author. Department of Medicine and Therapeutics, Carol and Richard Yu PD Research Centre, Prince of Wales Hospital, The Chinese University of Hong Kong, 30–32 Ngan Shing St, Shatin, New Territories, Hong Kong Special Administrative Region of China.

E-mail addresses: jchan@cuhk.edu.hk (J.C.N. Chan), philipli@cuhk.edu.hk (P.K.-T. Li).

International Diabetes Federation in 1993 as a quality improvement program.[5]

In Hong Kong, the wealth of real-world evidence from these registers confirmed the benefits of this data-driven care model which continued to drive system changes including the establishment of government-funded District Health Centres operated by paramedics to improve primary care through education, assessment and early screening. Meanwhile, more than 120,000 patients with diabetes from 11 Asian countries have benefited from the JADE Platform with built-in protocol, risk engines, reporting system and decision support with proven benefits on the control of risk factors, hospitalizations and clinical events including all-cause death.[6–8] With development of similar data-driven integrated care models in countries such as Japan[9] and China,[10] Asia has experienced the largest decrement in diabetes-related death rates amongst 16 high-income jurisdictions with territory-wide databases, where Hong Kong had the largest decline in annual diabetes-related death rate from 3% in 2000 to 1.3% in 2016.[11] Despite these encouraging trends, these registers had revealed the unmet needs in young-onset diabetes with its marked phenotypic heterogeneity and high prevalence of comorbidities including depression and high mortality rates.[12–14] These observations have inspired new initiatives in pursuit of precision prevention and care of young-onset diabetes.[15,16]

Actions driven by epidemic of diabetes and fragmented care in mid-1990

In the 1990s, rapid economic growth in Hong Kong was accompanied by a diabetes endemic affecting 7% of the population.[17] In this predominant Chinese population, diabetes was characterized by young age of diagnosis, high prevalence of family history and metabolic syndrome with propensity for kidney disease and cancer.[18] The heavily-subsidized healthcare system, modelled after the United Kingdom National Health Service, resulted in a significant rise in the number of patients attending the public sector, leading to short consultation time, lack of assessment, care fragmentation, poor doctor-patient engagement, treatment omission, suboptimal self-management and poor outcomes.[3]

From St. Vincent Declaration to Hong Kong Diabetes Register

In 1993, the St. Vincent Declaration of International Diabetes Federation recommended using diabetes centres, diabetes teams and diabetes care protocol to establish diabetes register to improve diabetes care.[5] In 1995, motivated by the Declaration and driven by observations of 50–80% lower death rates in patients receiving protocol-guided care in a clinical trial setting versus usual random care,[19] the Chinese University of Hong Kong (CUHK) Diabetes Research and Care team initiated a data-driven quality improvement programme at the Prince of Wales Hospital (PWH). The primary objective was to triage patients to different care providers based on their risk profiles and promote shared care between general practitioners (GPs) and hospital specialists. In this programme, endocrinologists designed case report forms and trained nurses to use simple procedures and equipment to perform one-stop multisystem assessment (eyes, feet, blood and urine) in patients with diabetes every 12–24 months. Changes to the clinic organization and workflow, designed to enable data collection for digitalization, marked the beginning of the HKDR (Table 1). These data were used to generate personalized report cards including risk factors, complications and target values with comments by endocrinologists. These reports were shared with patients and their doctors to promote shared decision-making and facilitate care triage[3,20] (Fig. 1).

From Hong Kong Diabetes Register to diabetes nurses and diabetes centres

Apart from promoting the HKDR to healthcare planners and policymakers, the CUHK team also organized Master/Diploma Programmes in Diabetes Management and Education with certified qualifications while the local endocrine society runs workshops to upskill nurses and advocate for system change to improve diabetes care.[23] In 2000, the Hospital Authority (HA) which operates all publicly-funded hospitals and clinics, incorporated the HKDR protocol into the territory-wide HA electronic medical record (EMR) system, created career paths for diabetes nurses, and established 18 hospital-based endocrinologist-led diabetes centres operated by diabetes nurses and healthcare assistants. Patients with diabetes from different medical clinics were referred to these centres for bi-annual multisystem risk assessment and education programmes (e.g., insulin injection, self-monitoring of blood glucose, peer support and nurse clinic) with nurses providing liaison between doctors and patients. In 2000–2012, 330,000 patients with diabetes underwent these assessments with improved control of risk factors and clinical outcomes. The proportion of patients achieving HbA1c < 7.0% increased from 32.9 to 50.0%, blood pressure ≤130/80 mmHg from 24.7 to 30.7%, and LDL-cholesterol < 2.6 mmol/L from 25.8 to 38.1%. Amongst patients with at least 15 years of diabetes, crude incidence of acute myocardial infarction decreased from 8.7 to 5.8, stroke from 13.5 to 10.1, kidney failure from 25.8 to 22.5, and death from 29.0 to 26.6 per 1000 person-year during the 13-year period.[24]

From HKDR to the Joint Asia Diabetes Evaluation (JADE) programme

In 2007, supported by an educational grant, the CUHK team established the Asia Diabetes Foundation (www.adf.org.hk) to design the first web-based JADE Platform. The

Since early 1990s	**Public hospitals/clinics in Hong Kong face growing burden of patients with diabetes and chronic diseases who require regular follow-up visits resulting in short consultation time, insufficient doctor-patient engagement, care gaps and health illiteracy with poor clinical outcomes**
1993	The International Diabetes Federation published the St Vincent Declaration advocating quality assurance programme for type 1 diabetes[5]
1995	CUHK initiated a research-driven quality improvement (QI) program by changing setting, workflow and team structure to establish the Hong Kong Diabetes Register (HKDR) at the Prince of Wales Hospital, the teaching hospital of CUHK[20]
1995	The QI program was complemented by a series of education and research programmes including the set up of a HKDR-biobank with patient consent. Regular meetings were held with hospital executives and primary care doctors to inform barriers and progress. The growing HKDR enables evaluation of the effects of this data-driven integrated care model which reveals care gaps and creates new knowledge for developing hypothesis and design of new programmes[1]
2000	Hospital Authority (HA) was established to take over the operation of all publicly-funded and subvented hospitals/clinics and provide universal healthcare to 7.5 million people in Hong Kong including the development of a territory-wide electronic medical record (EMR) system
2000	HA incorporated the HKDR protocol into the EMR system, created career paths for diabetes nurses and progressively set up 18 hospital-based Diabetes Centres operated by nurses, supervised by endocrinologists, to provide regular assessment, education and liaison between patients and doctors
2007	CUHK established the Asia Diabetes Foundation to develop the first web-based Joint Asia Diabetes Evaluation (JADE) Platform incorporating templates to guide data collection for risk categorization using HKDR-derived risk equations, data visualization, personalized reporting with tailored decision support to stratify risk, empower self-management and promote shared decision-making https://www.adf.org.hk/
2007	The web-based JADE Programme, which utilized anonymised unique codes for registration and de-identification, was implemented in 11 countries or jurisdictions in Asia benefiting 120,000 patients with proven benefits in improving control of risk factors and reducing complications, hospitalization and premature death rates[3]
2007	CUHK established a self-funded, community-based and nurse-operated diabetes centre to provide JADE-assisted evaluation and empowerment programme to patients through self-referral or referral by their doctors to complement private medical care https://www.hkido.cuhk.edu.hk/Centres/CUHK-Yao-Chung-Kit-Diabetes-Assessment-Centre
2009	HA adapted the JADE risk stratification concept and implemented a territory-wide Risk Assessment and Management Programme (RAMP) in primary care setting and thus created a territory-wide structured database for benchmarking and surveillance[21]
2016	CUHK curated the Hong Kong Diabetes Surveillance Database (HKDSD) from the HA-EMR system including 4 million people with blood glucose measurements, 0.8 million of whom had diabetes.[22] Extensive data analysis reported a 50–70% decline in incidence of diabetes complications and related death rates,[13] and organ-protective effects of treatment in real-world practice beyond that demonstrated in clinical trial setting; a high burden of depression and persistently high mortality rate in patients with young-onset diabetes was also revealed[14]
2017	CUHK performed comparative analysis and demonstrated the added values of JADE-assisted evaluation and empowerment programme implemented through public-private-partnership (PPP) in reducing hospitalization and death rates compared to public care alone[6]
2020	Supported by a government commissioned grant, CUHK conducted a 3-year randomized controlled trial including 884 patients with young-onset diabetes to evaluate the impacts of a multicomponent, multidisciplinary program using biogenetic markers on clinical and patient-reported outcomes (Precision Medicine to Redefine Insulin Secretion and Monogenic Diabetes-Randomized Controlled Trial (PRISM-RCT, NCT04049149) in Chinese patients with young-onset diabetes[15,16]
2022	A meta-analysis of 0.5 billion patient-years of data reported that Hong Kong had the largest annual rate of decline (−4% per year) of diabetes-related death rates from 2000 to 2016 among 16 high income countries or jurisdictions with territory-wide databases[11]
2023	Hong Kong Government set up 18 District Health Centers operated by nurses and social workers (https://www.dhc.gov.hk/en/index.html) and launched a territory-wide chronic disease co-care program through PPP starting with screening for diabetes in adults aged over 45 years to promote early detection, treatment and control https://www.primaryhealthcare.gov.hk/cdcc/en/gp/introduction.html
2024	Supported by the Hong Kong Jockey Club Charities Trust, the CUHK designed and launched a 4-year territory-wide Precision Prevention Programme on Young-Onset Diabetes using biogenetic markers, team-based care enhanced by digital technology implemented through PPP in 9000 young adults aged 18–44 years to detect, prevent and treat young-onset diabetes early (JC-PPPYOD: clinical trial registration: NCT06693934)

Refer to Supplementary Table S2 for additional references.

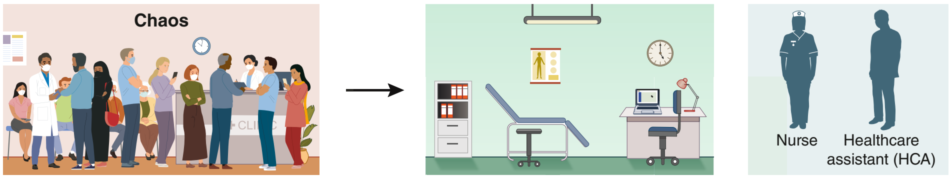
Table 1: **Evolution of a research-driven quality improvement programme beginning with the establishment of the Hong Kong Diabetes Register (HKDR) in 1995 which evolved to become a regional web-based Joint Asia Diabetes Evaluation (JADE) Programme and a territory-wide Hong Kong Diabetes Risk Assessment and Management Programme (RAMP) that facilitate regular patient evaluation and personalized management, complemented by a professional and patient education and engagement programme with ongoing evaluation to inform decision-making at all levels and discover new knowledge for implementation.**

latter incorporates a portal for data entry with built-in HKDR risk algorithms, data visualization indicating trends of modifiable risk factors and 5-year probabilities of complications with decision support based on attained treatment targets (Supplementary Figure S1). The JADE Programme was implemented by doctor-nurse teams, benefiting more than 120,000 patients in different healthcare settings across 11 Asian countries. Apart from confirming the Asian phenotypes with high prevalence of young-onset diabetes[12] and kidney disease,[25] participation in the JADE Programme improved control of multiple risk factors, enhanced self-management, facilitated early intervention (e.g., addition of statins and renin-angiotensin system inhibitors) and reduced major events including premature death.[6–8,26,27]

In the evaluation of 16,624 Chinese patients with type 2 diabetes followed up between 2007 and 2017 in Hong Kong, patients participating in the JADE Program had 20–50% risk reduction in major events including death compared to patients who only participated in the RAMP with less structured follow up, highlighting the importance of using personalized data to empower and engage the patients and care professionals to take early actions.[6] In 2016, the CUHK team curated data from the HA-EMR, set up the Hong Kong Diabetes Surveillance Database and reported 50–70% decline in major events major events-related death in 800,000 patients with diabetes since 2000.[22]

Public-private partnership and primary care reform

In Hong Kong, 50% of doctors work in the private sector. In 2007, supported by a donation, the CUHK team established a self-funded community-based



Transform the setting of a busy clinic to a risk assessment unit

Basic requirements of a risk assessment unit:
- Small room and simple tools, e.g. monofilament, tuning fork, Snellen chart
- Office equipment, e.g. computer, printer
- Pre-booking and patient instructions
- Case report forms to guide history-taking and structured clinical assessment including collection of blood and urine samples, and eye* and feet* examination

*In resource-restrained settings, doctors can examine the eye using an ophthalmoscope and perform clinical examination of the feet (pulse and sensation) in a less-hassled environment with the nurses/HCA organising the workflow. The data are entered into a program, e.g., Microsoft Access, to create a database with reporting.

Primary roles of doctors:
- Make diagnosis and clinical decisions, and monitor progress
- Prescribe medications
- Refer for education
- Refer for assessment
- Provide on-job training
- Support nurses/HCA

	Mon	Tue	Wed	Thu	Fri
Number of patients who undergo yearly or bi-annual structured assessment	4–6	4–6	4–6	4–6	4–6
Booking, data entry and print report with review and comments by doctors	✓	✓	✓	✓	✓
	Lunch				
Group education and give report		10–15		10–15	
Individual consultation	✓		✓		✓
Liaison between patient and doctor	✓	✓	✓	✓	✓
Special programs	e.g. injection class, peer support program, YOD, DKD				

Content for the above figure is excerpted from Chan JCN, et al. *Curr Cardiovasc Risk Rep* 2011; **5**: 230-9

YOD = young-onset diabetes; DKD = diabetic kidney disease
1 nurse-HCA team supervised by a doctor can manage 800 to 1000 patients

Fig. 1: The original design including changing setting, reorganizing workflow and training non-medical personnel to create the Hong Kong Diabetes Register (HKDR) in 1995 at the Prince of Wales Hospital, the teaching hospital of the Chinese University of Hong Kong, has since expanded to become a standard service in Hong Kong while the ongoing evaluation of the register and related databases accompanied by a biobank continues to create new knowledge to unravel the complexity of diabetes and its complications.

diabetes assessment centre operated by nurses, with supervision from endocrinologists, to provide JADE-assisted evaluation, empowerment and engagement programme on a fee-for-service basis to complement private medical care. Compared with usual HA care, the JADE-assisted care model implemented through public-private-partnership (PPP) was more effective in reducing hospitalization and death rates.[6] In 2009, the HA adapted the risk stratification protocol in the JADE Programme to launch the RAMP in the primary care setting with proven benefits and cost-effectiveness.[21] In 2023, the Hong Kong Government established 18 District Health Centers (DHC) operated by nurses and social workers, and launched a 3-year territory-wide diabetes detection and treatment programme in adults aged over 45 years with the DHC providing assessment and education to complement private medical care (Supplementary Figure S2). In 2024, supported by a major charity, the CUHK research team launched a precision prevention program on young-onset diabetes using biogenetic markers, digital tools and collaborative care through PPP (Table 1). In a meta-analysis of 0.5 billion person-years of people with diabetes from 16 high-income jurisdictions with national/territory-wide databases, Hong Kong had the largest decrement in death rates from an annual rate of 3% in 2000 to 1.3% in 2016.[11]

Turning challenges into opportunities for transformative care

The shortage of manpower and growing number of patients suffering from preventable complications were pain points that underlie the reform of diabetes care at the PWH. Apart from the St. Vincent Declaration,[5] the life-saving nature of team-based structured care in a clinical trial setting versus random care in busy clinics[19] and the benefits of using data (together with biobanks) to define causes, trajectories and consequences of diabetes are additional motivations.[18] To this end, the establishment of the HKDR in 1995 had a very humble beginning when Hong Kong was only a middle-income city where diabetes was considered a Cinderella subject – important but not sufficiently urgent to demand huge attention.

When the HKDR was first established in 1995, the CUHK-PWH care team used existing resources to reorganize care and proactively set up dialogues with GPs and administrators to explain the importance of risk stratification, quality assurance and professional training to implement diabetes shared-care programme. Despite multiple barriers at a system level, such as separate drug formularies and varying payment structures between different care settings, this has alerted the administrators a need to strengthen the system for seamless care with risk assessment as a key component[20] (Supplementary Table S1).

From a research perspective, the CUHK team continued to use university seed funds, competitive grants, donations, proceeds from courses and conferences as well as industry through clinical trials and investigator-initiated studies to build infrastructures for setting up registers, cohorts and biobanks with knowledge transfer including establishment of research institute, charitable foundation and biotech companies to develop a workforce for implementing and evaluating the impacts of precision prediction, diagnosis, prevention, and treatment of diabetes.[28] Supplementary Table S2 lists some key references related to the HKDR and its ramifications including career development of knowledge workers and new research and quality improvement programmes, inspired by knowledge learnt from the HKDR and related studies.

Lessons learnt from the evolution of diabetes care in Hong Kong

Every person with diabetes has a unique set of risk profiles that need to be measured, monitored and managed to enable personalized care. Empowerment is a cornerstone in diabetes management. The cognitive, psychological and behavioral determinants call for personalized data to empower patients through regular feedback and support. These data contribute to a register which can be used to benchmark performance, identify care gaps and demonstrate the value of data-driven care to align the goals of patients, practitioners and payors, while the accompanying biobank represents a valuable resource to refine the diagnosis, classification and treatment responses in pursuit of precision medicine.[15]

Change was never easy but with the right timing, people and setting, small changes can lead to paradigm shift with new thinking, learning and action. In this data-driven care model, nurses play key roles in organizing workflow, performing structured assessment and gathering data, supported by medical specialists, to drive actions at all levels. Notwithstanding the importance of advocacy from individuals and organizations, notably support by philanthropist and foundations, is critically important to scale the project for demonstrating its value to payors or policymakers and increasing its sustainability. To this end, the commitment of executives who can effect change at a system level is vital. These decision-makers can be receptive to practical solutions, especially if supported by data demonstrating improved outcomes and cost-effectiveness.

Doctors design, evaluate and advocate for innovative, value-based, patient-centred care

Doctors who have the integrated knowledge of human biology, clinical medicine and treatment are in a privileged position to diagnose, treat and evaluate care strategies to benefit patients and those at risk. The epidemic of diabetes is a public health crisis arising from complex interplay between society and human behaviors, posing multiple challenges to individuals with a biological predisposition. To this end, doctors must continue to reflect, learn and improve in order to lead, design and experiment context-relevant solutions. Most importantly, they must be able to translate their knowledge through team-building to execute actions and create partnerships to make positive changes.

Contributors

JCNC conceptualized the model, provided the data, prepared the draft and finalized the manuscript. All other coauthors have given comments and their approval for submission of the final version. JCNC, MC and PKTL had the final responsibility of submitting the paper for publication. Data contribution or access does not apply to this commentary.

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Declaration of interests

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Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.lanwpc.2025.101505.

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