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## Comprehensive program development for congenital heart disease in the United Arab Emirates and Singapore

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### Keywords

healthcare organization, congenital cardiac surgery, infrastructure, demography

## Abstract

**Background/Objective:** Establishment and development of tertiary-care centers for congenital heart disease (CHD) face multiple challenges as they need to be accessible, affordable/sustainable and provide the best possible outcomes. We report our experience of foundation a new tertiary-care CHD center in the United Arab Emirates (UAE) and program development in Singapore.

**Methods:** The prevalence and incidence of CHD in the context of local sociocultural environment was reviewed. Having established program elements of team, premises, and workflow, the quality assurance system was established and maintained by outcome analysis, and continuous audit in comparison with international databases.

**Results:** Consanguinity, segregated population pattern, and low prenatal screening rate increased the incidence/prevalence and complexity of CHD in the UAE. Increasing patient-load, strict professional working environment, strong governmental financial mandate for care appointed the centre into a market-leading position in the UAE. From the program start to 2020, we performed 4655 congenital cardiac operations with a median complexity=7.99 (v. international database mean=7; scale: 3-15) and hospital mortality=2.73±0.79% (v. expected mortality=3.41%). Singapore has a highly-developed, regulated, still competitive healthcare infrastructure, but low birth-rate and low prevalence of CHD represent challenges for program development started in 2021. Preliminary results of Singapore program development demonstrate improved team coherence, 60% growth of caseload, increasing case-complexity (from median=6.9 to 8.7), introduction of minimally invasive techniques (>80%) at preserving optimal outcomes (hospital mortality=2.5%). Additional CHD caseload from underserved regions could contribute to team performance maintenance to ensure the best possible patient and program outcomes in Singapore.

**Conclusion:** New and/or developing CHD centers face different challenges depending on the sociocultural and economic environment they function in. External demographic factors, case-load, complexity, referral patterns, healthcare financing structure are difficult to adjust; internal factors: program structure, quality assurance, professional working framework are subjects for improvement.

## Introduction

New and developing centers for congenital heart disease (CHD) encounter a triple challenge as they aim to be (1) accessible to all ages and complexities and social backgrounds; (2) financially affordable/sustainable; and (3) they are expected to produce the best possible outcomes. This triple aim of modern healthcare is configured by external and internal factors. Demographic patterns, CHD prevalence/incidence, primary diagnosis framework and referral patterns presenting as public health demand are external factors that translate into case-load and complexity. Healthcare financing structure - acting as external/internal factor simultaneously - both regulates affordability for patients and families; and institutional sustainability. Internal factors, e.g., the characteristics of the actual multidisciplinary team, local quality assurance system and professional working framework affect the program structure<sup>1</sup>.

The triple aim of accessible, affordable and high-quality congenital cardiac services is difficult to achieve in the real world that presents with global inequality of care<sup>2,3</sup> and significant CHD populations are underserved worldwide<sup>4</sup>. Sending patients abroad for treatment is expensive, represents a temporary and individual solution, non-available for all; or it is simply impractical/impossible for time and/or geographical constraints. The establishment and development of services locally have been endeavored in the form of charity missions, cooperation/coaching programs, and foundation by resident international teams (**Table 1**).

## Objective

We report two case scenarios for comprehen-

sive CHD programs by resident teams: (1) foundation of a new tertiary-care CHD center in the United Arab Emirates (Sheikh Khalida Medical City, Abu Dhabi; SKMC, UAE) and, (2) program development in Singapore (National University Heart Centre, NUHCS, Department of Cardiac, Vascular and Thoracic Surgery).

## Materials and methods

Demographic patterns and prevalence/incidence of congenital heart disease was studied in national/international information sources<sup>5,6</sup> to estimate CHD public health demand. In the program establishment scenario (SKMC), a local pediatric cardiology professional network was created first to establish primary diagnosis framework and referral patterns and follow-up pathways. As part of a feasibility study, healthcare financing structure was explored. An Institutional and organizational setting was established. Program preparation addressed facilities, equipment and the team from the viewpoint of continuum-of-care, expected caseload and case mix. Various segments of care, e.g., dedicated operating room, intensive care unit (ICU), high-dependency unit (HDU) and paediatric ward were assigned and equipped. Meantime, the international multidisciplinary team was recruited.

In both program establishment (SKMC) and development (NUHCS) scenarios, creation a professional working framework, rules of strict daily routines, multidisciplinary cooperation with team-empowerment, a robust quality assurance system including key performance indicators were agreed in accordance to international recommendations for congenital cardiac centers<sup>7,8</sup>. We also employed various strategic, tactical and operational models to develop the specifics of a comprehensive service for CHD. Strategic models e.g., product/market grid, core compe-

**Table 1:** Advantages and disadvantages of different formats of CHD program development

Format	Benefits	Disadvantages
Visiting team missions	Individual patient benefit	No continuity-of-care Surgical safari Service disruption
Cooperation programs	Continuous external coaching Local talent advancement High professional standards	Brain-drain of local talent Applicability of adopted modalities
Resident teams	Continuity-of-care Local talent recruitment Organic program development	Sensitive financial sustainability Dependence on institutional support Possible slow program development

tencies, scenario-planning, etc. were employed in the planning/designing phase<sup>9</sup>. In the production phase, tactical models were added: e.g., 7-S framework, learning-v-traditional organizations for improving team dynamics<sup>10</sup>, etc.; and, the strategic model of strengths-weaknesses-opportunities-threats (SWOT) analysis<sup>9</sup>. Operational models, like root-cause-analysis served as continuous audit in form of a plan-do-check-act cycle<sup>11</sup>. Quality assurance was maintained through weekly multidisciplinary team conferences, performance reviews, journal clubs. Clinical outcomes were measured with those in international databases<sup>12,13</sup>. At SKMC program establishment, a special dispensation was sought with the health government to ensure the financial sustainability of the newly established CHD program.

## Results

### 1. Establishment of a comprehensive service for CHD in the UAE

Historically, individual Emirati CHD patients were sent abroad for surgery/treatment; and no dedicated CHD service existed for resident non-nationals in the UAE. Our comprehensive program was established at Sheikh Khalifa Medical City (Abu Dhabi, UAE), a 588-bed, JCI-accredited government teaching hospital<sup>14</sup>. This flagship facility of UAE healthcare already hosted numerous tertiary-care surgical services: e.g., solid-organ transplantation, spine surgery, neurosurgery, etc. Our new, tertiary-care congenital cardiac program integrated into a cardiac institute, next to adult cardiology/cardiac surgery and a paediatric department already in existence.

Preliminary market research showed significant public health demand for CHD treatment and a medium-size, nationwide tertiary-care center was envisioned. A referral/admission protocol was circulated among a network of pediatric cardiologists and possible referring hospitals informing 24/7 availability of services. On the receiving side, in-house paediatric cardiologists were put in charge who communicated with critical care physicians and surgeons. During a 4-month-long preparation period a continuum-of-care protocol was drawn up for four complexity-based expected patient pathways: simplest (closed procedures), simple (e.g., ASD, VSD repairs), com-

plex (e.g., tetralogy of Fallot-repair, bidirectional/total cavopulmonary connection), most complex (neonatal open-heart procedures, e.g., arterial switch, Norwood procedure). These pathways prompted contingency aspects of the program e.g., dedicated OR, integrated pediatric cardiac ICU/HDU (9+6 beds), and service modalities that encompassed non-invasive/invasive diagnostics, catheter-based interventional, hybrid and surgical arms along with ECMO/ECLS. The pediatric cardiac multidisciplinary resident team comprised of 88 team members of 28 nationalities, speaking 39 languages that became a very cohesive resident group with no fluctuation of key medical professionals.

At the time of the founding of our CHD program, no comprehensive health insurance system existed in the UAE. Emirati nationals (15-18% of the population) were covered by statutory rights of their citizenship; however, residents (82-85%) lacked healthcare coverage. Pertinent UAE Health Law defined congenital heart disease as a '*life or limb emergency*' that allowed to admit *all* patients with CHD to SKMC. This mandate from the Health Authority Abu Dhabi ensured the financial sustainability of the service<sup>15</sup>. With the introduction of mandatory national insurance system (2011) and concomitant formation of various insurance companies, eligibility criteria for mandated care progressively stiffened and the government's financial involvement gradually decreased. (**Figure 1**)

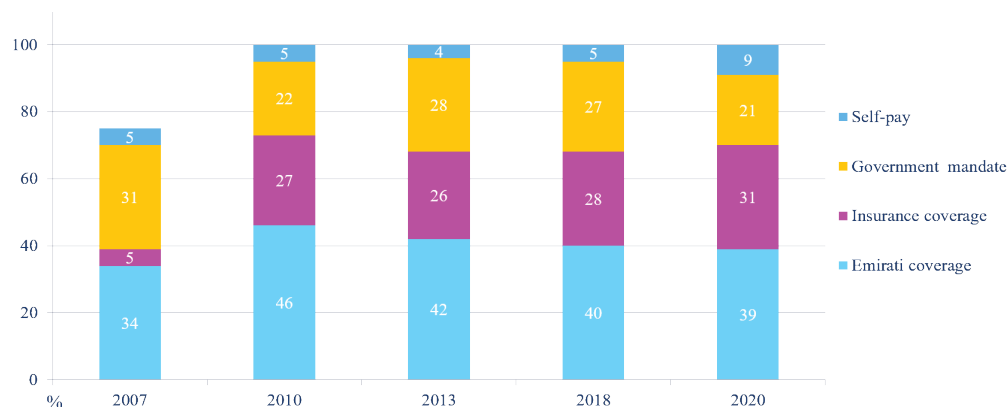
Annual surgical volumes increased linearly in the formative years of the program (**Figure 2**). Subsequent plateau phase is attributed to a number of intrinsic and extrinsic factors. Institutional reorganization into separate paediatric cardiac surgery, anaesthesia, critical care, etc. divisions, rather than an integrated paediatric cardiac institute acted as an intrinsic barrier. Slowing intergovernmental projects reduced the influx of CHD patients from neighbouring countries and thus hampered SKMC's evolution into a regional center of excellence.

SKMC has been a sole provider for complex CHD in the UAE; that fact was represented in the distribution of age groups, complexity and acuity of the surgical procedures. Data divide into two

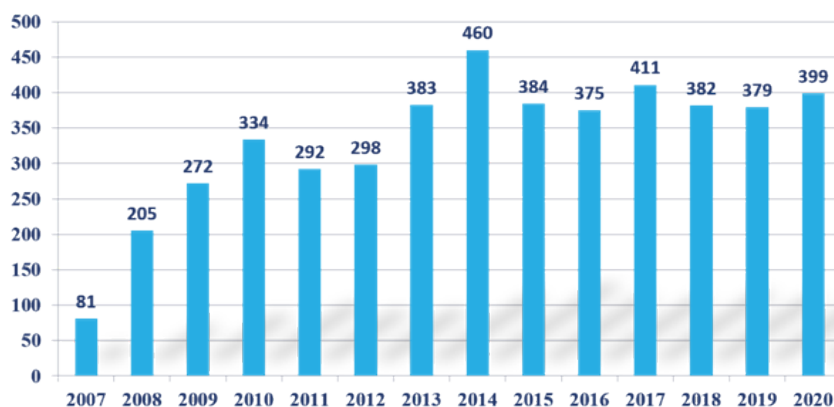
distinct cohorts: (1) neonates significantly higher complexity and acuity and (2) patients above 1 year of age. Survival, however, has not been significantly different between the groups (**Table 2**).

Higher representation of neonates and patients less than 1 year of age (71.1%) may ex-

plain the overall higher complexity in the surgical series. Comparison of historical local data on median complexity and hospital mortality rate with international dataset<sup>16</sup> shows that local complexity exceeded the Database median value of 7.0 (Aristotle Basic Complexity Score: 3-15), whereas outcome represented by hospital mor-



**Figure 1.** Financial coverage at SKMC Paediatric Cardiac Surgery, 2007-2020. Courtesy of Ms Huda Attiah



**Figure 2.** SKMC annual surgical volumes (2007-2020, N=4655)

**Table 2.** Distribution of age groups, complexity and acuity of CHD patients operated at SKMC (2007-2020, N=4655)

Age groups	Neonates	1month-1year	Beyond 1year	Statistical significance <sup>a</sup>
N=4655; primary procedures	1499 (32.2%)	1810 (38.9%)	1346 (28.9%)	Emergency neonates v electives beyond 1year
Elective	158	1091	1102	OR:366.08;
Urgent	1021	596	190	p-value:0.001
Emergency	320	123	54	
Complexity (mean, SD)	8.78 SD2.84	7.45 SD2.14	7.05 SD2.32	t-value:7.21381; p-value:0.00001
Survival (%)	96.92	97.93	98.24	OR:2.46; p-value:0.116; NS

'Elective' is defined as the surgical procedure is to be performed in the preferred time frame; 'urgent': within the same hospitalization; 'emergency': within 24-48 hours. Complexity is displayed on a continuous range of 1.5-15. <sup>a</sup>A two-tailed, paired Student's t-test was used for the comparison of numerical variables. P-value <0.05 was considered statistically significant. Categorical data were analysed by khi-square test and odds-ratio is provided (OR). NS: non-significant, SD: standard deviation

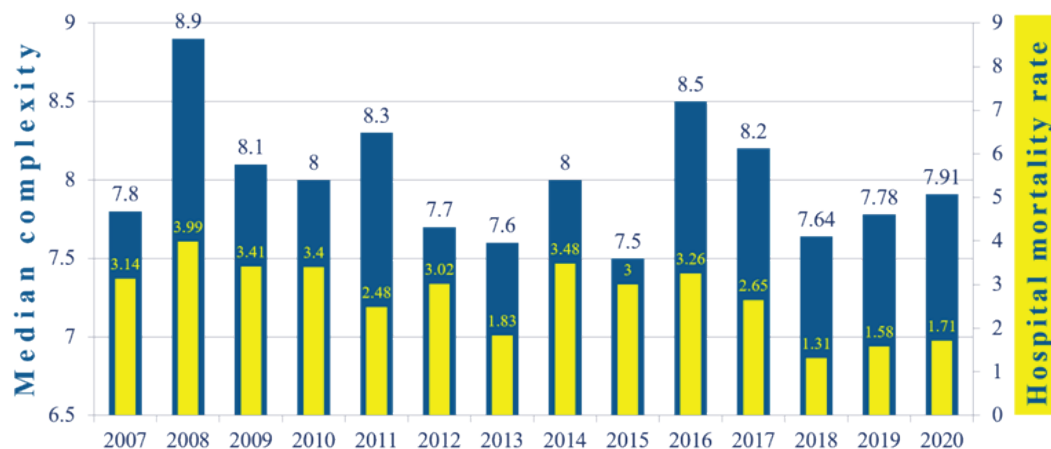


tality remained at par level of the international figures<sup>13,17</sup> (**Figure 3**).

In want of a comprehensive service, numerous new modalities were introduced, e.g., 24/7 ECMO/ECLS service that opened for both perioperative cardiac and respiratory indications<sup>18</sup>. Similarly, hybrid techniques and intraoperative visualization, preoperative planning with 3D-printed patient-specific anatomic models were added<sup>19</sup>. Due to the sociodemographic dynamics of the UAE, Emirati patients were always overrepresented (34-46% in our surgical population v. 15-18% of Emiratis in the general popula-

tion). Adult congenital cardiac patients were still fewer and their gradual increase was expected once the patients locally operated on reached adolescent age<sup>20</sup>.

A strengths - weaknesses - opportunities - threats (SWOT) analysis of the SKMC program (**Figure 4A**) reveals strengths as an established provider recognized by the community (both professional and public). A cohesive multidisciplinary team offers multimodality treatment for the entire spectrum of age and complexity. The weaknesses are related to the labor/cost intensive, staff/equipment sensitive high case-mix



**Figure 3.** Median Complexity according to Aristotle Basic Complexity score and hospital mortality rates at SKMC Paediatric Cardiac Surgery, 2007-2020.



**Figure 4.** Comparative SWOT analysis. A: pediatric cardiac program establishment at SKMC, Abu Dhabi, UAE. B: program development at NUHCS, Singapore.

Abbreviations: CHD: congenital heart disease, COVID-19: coronavirus disease, CTVS: Department of Cardiac, Thoracic and Vascular Surgery, MDT: multidisciplinary team

index. Established treatment modalities, e.g., neonatal open-heart surgery, hybrid program, ACHD/GUCH-programme, ECMO, etc. create opportunities. Despite the service model is suitable for receiving trainees and it presents franchise opportunity (i.e., establishment of affiliated centers), the lack of local talent interest, and therefore, no incentive for education, poses a threat for long-term organic development.

## 2. Singapore program development

Singapore has a world-renown healthcare infrastructure and elaborated financing system that covers all her citizens and long-term residents<sup>21</sup>. Healthcare financing is governed by the principles of individual responsibility for health, patient co-payment to minimize moral hazard and wastage and government subsidies to keep basic healthcare affordable<sup>22</sup>.

The National University Heart Centre (NUHCS) - ranking 56<sup>th</sup> among the World's Best Specialized Hospitals<sup>23</sup> - is a tertiary referral hospital and academic medical centre affiliated with the National University of Singapore (NUS). The paediatric cardiac surgical program is part of the Department of Cardiac, Thoracic and Vascular Surgery (CTVS) which pioneers many innovative modalities, e.g., minimal invasive cardiothoracic surgery, hybrid and robotic programs, aortic surgery, etc. Paediatric and congenital cardiac surgery has a long tradition at NUHCS CTVS<sup>24</sup>; however, it has remained a small program (there were 1081 surgeries performed for CHD between 2009-2020). A new vision for program development to become a provider of choice for complex CHD was initiated in 2021. Realizing that plan relies on 24/7 accessibility for emergency/urgent and elective CHD treatment. As treating CHD is a '*commitment for life*', the continuum-of-care spans from preoperative preparation throughout the intervention and postoperative period to the patient's journey back to and in the community. Family education, and home-monitoring is an integral part of that philosophy. Treatment is provided from neonatal complex repairs to adult congenital cardiac care (GUCH). A full spectrum of modalities is available, e.g., non-invasive/invasive diagnostics, catheter interventions, hybrid procedures, ECMO/ECLS, etc. Outcomes are measured at multidisciplinary team conferences,

and performance reviews with intraoperative video recordings on a weekly basis. Expected/observed progress and outcomes are also matched with international databases.

Initial (2021-2022) results of program development in Singapore do not allow a direct comparison with data from UAE, however, a comparison with institutional historical data<sup>24</sup> demonstrates a favorable trend, e.g., operative activity increased by 60% in the first two years - partially due to previous backlog; median case complexity also increased from median 6.9 to 8.7 (Aristotle Basic Complexity Score: 3-15) by internal audit. New procedures and modalities e.g., *en bloc* double-root rotation, hybrid approach (e.g., periventricular muscular VSD closure, intraoperative stenting, etc.) were introduced. Outcomes (hospital mortality=2.5%) are at par level with international database. Preoperative planning is supported by surgical emulation on 3D-printed prototypes and holograms. With cross-fertilization from a world-class minimally-invasive program at adult CTVS<sup>25</sup>, this modality gradually finds its place in our pediatric practice. Currently, over 80% of the surgeries are performed as less-invasive procedures with minimal skin incision, with alternative perfusion techniques. Intraoperative video-recording of all procedures help performance improvement, training and education.

Training the next generation of surgeons is a key aspect of program development at NUHCS. Our team participates in postgraduate training schemes at both national (Postgraduate Medical Education, Specialist Accreditation Board of Singapore) and international levels (NUH International Training Fellowship). In a broader sense, we aim not just to treat but educate both professionals and the community.

A SWOT analysis of pediatric cardiac surgery work-in-progress at NUHCS is summarized on **Figure 4B**. NUHCS's multidisciplinary team has its strengths in its cohesion, open communication and excellent team-dynamics; however, the institutional organogram dictates that team members need to trespass their territorial boundaries to cooperate and improve quality of service. The team participates in charity mis-

sions (e.g., at Sri Satthya Sanjeevani Children's Heart Hospital, Suva, Fiji) where participants act out of their usual comfort zone in a high-volume environment; these avenues offer important opportunities for team-building and enhancing responsibilities. NUHCS pediatric cardiac services have a competitive edge of offering comprehensive services from pre/neonatal age to the grown-up congenital heart population by having a strong support from CTVS and its alliance with Khoo Teck Puat - National University Children's Medical Institute. Involvement into the planning for the new National University Hospital's infrastructure can reinforce mutual interdependence and contribute to a unique model of care. Affiliation with the National University of Singapore boosts research and education. Our current high case mix weakens optimal utilization of resources that could be ameliorated by reopening medical tourism. Singapore's low prevalence of CHD and consecutive smaller patient population - that threatens with suboptimal outcomes - mandates cooperation and networking among all involved entities at both institutional and national level. Concentrated action, i.e., cooperation seems the only viable option for nurturing local talent and training the next generation of professionals.

## Discussion

Pediatric and congenital cardiac surgery is an essentially multidisciplinary discipline that re-

quires high investment, for being quantity-quality intensive, it poses a high threshold and faces high public expectations. **Table 3** illustrates both UAE and Singapore are high-income countries<sup>26</sup> that - theoretically - provides a strong financial basis for world class CHD care.

It is the local sociocultural context that a successful CHD service also needs to adjust and integrate into. The United Arab Emirates has a special social fabric as indigenous Emiratis (15-18% of the country's total population) and resident immigrants communities form separated population groups with little reproductive mixing<sup>27</sup>. Consanguinity is traditionally and culturally prevalent<sup>28</sup>. Previously high birth rate (16.5/1000 population; 2002) decreased (10,02/1000 population; 2022) to the level of the European average (10.42/1000 population; 2022)<sup>29</sup>. Religious creeds would not allow termination of pregnancy<sup>30</sup>. All these aspects contribute to an increased prevalence of CHD, and enhance their complexity<sup>31</sup>. Infant mortality rate radically decreased and has now reached to the range of the developed countries, signifying a rapidly advancing healthcare infrastructure<sup>32</sup>.

Singapore's cutting-edge healthcare infrastructure is organized in three clusters serving a population (5.98m; 2023) of Chinese (74.3%), Malay (13.5%), Indian (9%), and other (3.2%) subgroups with significant mixing and low consanguinity. Birth rate is at a low level and further

**Table 3.** Comparison of population demographics, economic data in the United Arab Emirates and Singapore in 2020<sup>26</sup>. Estimates of CHD incidence and expected service provisions are based on the literature and international recommendations<sup>1,6</sup>

	UAE	Singapore
Population	9.973.449	5.975.383
Median age (years)	38.4	35.6
Birth rate (1/1000 population)	10.76	8.94
Fertility rate	1.62	1.17
Infant mortality (1/1000 births)	5.06	1.54
GDP/capita (US dollars)	69.700	106.000
Healthcare expenditure (% of GDP)	5.5	6.1
Births	97.572	35.605
Neonates with CHD (1/170 live births=0.58% <sup>1</sup> )	566	207
Need for primary CHS (66% of CHD patients need surgery/year <sup>6</sup> )	374	136
Staged/GUCH (10%/year <sup>6</sup> )	38	14
Total CHS national need/year	412	150

Abbreviations: CHD: congenital heart disease, CHS: congenital heart surgery, GDP: gross domestic product, GUCH: grown-up congenital heart disease



decreasing (8.41/1000 population; 2022)<sup>33</sup>. Pre-natal discovery of CHD is about 95%<sup>34</sup>; there is a general predilection for termination of complex anomalies (e.g., HLHS)<sup>35</sup>. It is estimated around 200 neonates are born with CHD in Singapore annually. National demand for congenital cardiac surgery (even with staged and redo operations) does not meet the minimum output requirements of 250 operations for a tertiary congenital cardiac centre<sup>7</sup>. Singapore, a well-established hub for medical excellence had attracted medical tourism that somewhat compensated for the low caseload; however, influx of foreign patients completely halted during the COVID-pandemic. Increasing treatment costs also affect Singapore's competitive edge and hamper recovery of medical tourism.

Low caseload and case mix can lead to mediocre outcomes, a quantity-quality relationship often stated in congenital cardiac surgery<sup>7,36</sup>, that prompts policymakers to centralize and professionals - ideally - to cooperate<sup>3,37</sup>. Centralization and cooperation could become entangled in politics, institutional pride and pursuit of revenue<sup>3</sup>. Historically, congenital cardiac surgery is embedded in (1) children's hospitals where all the necessary allied disciplines are available; (2) conjoined to large adult cardiothoracic surgical departments where the paediatric subspecialty can rely on adult support services, supply-chain, etc.; or (3) - in case of major units - it functions as a stand-alone, dedicated congenital heart centre (of excellence) providing the full continuum-of-care. For a highly specialized discipline, congenital cardiac units are typically affiliated to teaching/university hospitals. Without denying the importance of the external and organizational factors, we propose that internal team dynamics, strict professional protocols and work ethics will ultimately decide the success of any congenital cardiac program. Team empowerment capitalizes on the professionalism, dedication and motivation of individual team-members and it acts for continuous improvement of a changing modality in a changing world (e.g., emergence of GUCH population, minimally-invasive hybrid modalities, etc.). Changing times also accentuate the moral responsibility for nurturing the next generation of professionals. Both program establishment (SKMC) and program development (NUHCS)

projects progressed in the form of *learning organizations v. traditional organizations*<sup>10</sup>. In learning organizations departmental boundaries are permeable in order to maximize skills to enhance creativity and learning and to ensure integrated processes as an approach to complex activities. A pediatric cardiac multidisciplinary team is the proper example of open, multifunctional networks among the divisions and departments and beyond.

Authors acknowledge the limitations of these two case presentations owing to personal experience and involvement in the respective programs that also bear the characteristics of real-time snapshots.

We conclude with corresponding quotes by Sheikh Zayed al Nahyan and Lee Kuan Yew founding fathers of the United Arab Emirates and Singapore that resonate the importance of education and handover to the next generation: *"The real asset of any advanced nation is its people, especially the educated ones, and the prosperity and success of the people are measured by the standard of their education."*<sup>38</sup> (Sheikh Zayed al Nahyan, 1918-2004). *"You begin your journey not knowing where it will take you. You have plans, you have dreams, but every now and again you have to take uncharted roads, face impassable mountains, cross treacherous rivers, be blocked by landslides and earthquakes. That's the way my life has been."*<sup>39</sup> (Lee Kuan Yew, 1923-2015).

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## Conflict of interest statement

Conflict of interest: none declared.

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