Detailed account of the provisions of the Doha Donation Accord

Some key contextual information

- **Expatriate workers**
- Labour and Human Resources Laws governing expatriate workers dictate that their visa sponsors must assume responsibility for repatriation of coffins or decent burial, healthcare insurance, sick leave and so on.

- **Social work program at HMC**
- The cases of all patients who die in the HMC hospitals are reviewed by the hospital's social work program (SWP). Where families are deemed eligible to receive welfare support, this is usually arranged by the SWP in association with various Qatar charities, which have offices in various countries (see www.qcharity.com/en). The program has offices in numerous countries, and the hospital uses a detailed book with monthly benefits set for each country according to number of orphans, widow, handicaps, etc. As an alternative to regular income payments, families may be offered the opportunity to access micro-financing, e.g. to buy livestock to develop a new income source.

- **Deceased donation process at HMC**
- All patients in the ICU with fixed dilated pupils and signs of imminent death are referred to the transplant/donation coordinator team. The team makes no contact with these patients until such time as they have been declared brain dead (now "potential donors") and the ICU team has broken this news to the family. The family will be approached in their own language (in person or via telephone) by the donation team.
- All potential DD families are now approached regardless of the potential donor's citizenship or VIP status.

- **Costs of donation and transplantation care in Qatar**

- All hospital expenses of donation and transplantation (preparation, procedures and postoperative) are free, being covered by Hamad Medical Corporation for all citizens and expatriates resident in Qatar.

- Dialysis costs for expatriate residents are paid by the Institute of Social Development to the dialysis units.

- Visitors to Qatar pay for dialysis, but if poor may request and usually receive financial support from charities.

1 To whom does the Doha Donation Accord apply?

1.1 Often, there are lovely sounding policies that apply only to a select group, while other groups (usually non-citizens) are subject to different rules, with inferior levels of protection, rights and care. Qatar is a country where over 80% of residents are non-citizens, and the majority of these seem to be poor, perhaps illiterate labourers who lack any political rights in Qatar. In contrast, the citizens are extremely wealthy. There are plenty of countries with far less extreme inequalities in wealth and political enfranchisement, in which such vulnerable non-citizen groups lack equitable access to health, let alone transplantation. I admit I came here with a fairly high level of concern (or cynicism) that some elements of the Accord might be too good to be true.

1.2 The Accord applies to all Qatari citizens and all residents, i.e. those with working visas, not to visitors.

2 Are living donors offered anything that might represent an incentive for donation inconsistent with the Declaration of Istanbul's principles?

2.1 LD receive free medical care as appropriate during evaluation, procurement and follow up care.

2.1.1 Not an incentive. All citizens and residents are covered by health insurance as a matter of law while in Doha. Wealthy Qataris and impoverished Bangladeshi construction workers are cared for in the same wards at HMC by the same doctors.

2.2 LD receive disability insurance in case of complication arising from donation.

2.2.1 Not an incentive. The HMC provides disability insurance covering all patients who suffer a complication as a result of receiving medical care.

2.3 **LD receive comprehensive health insurance for life* (*assuming residence in Qatar).**

2.3.1 This has advantages over universal health insurance coverage for all residents, in that it provides "extras" such as dental care or treatment in a single room ward when hospitalized.

2.3.2 **Not an incentive**. Given ready availability of health care as part of the regular insurance program, the marginal advantages of "comprehensive" – which would only apply for the duration of the LD's employment in Qatar (i.e. non transferable on returning to home country), seem unlikely to motivate donation.

2.3.3 *Isn't it technically a material advantage?* So marginal is the difference between "comprehensive" and standard insurance, at this time in Qatar it's not likely to provide an effective incentive. Notably, this would not be the case in countries such as Australia, where all are covered by health insurance, but offering comprehensive private health insurance may represent a substantial financial incentive for the poor.

2.4 LD receive an allocation priority if they later develop end stage organ failure

2.4.1 This reciprocity reward or incentive reflects Proposal 5 of the Declaration of Istanbul.

2.5 First degree relatives or spouses of Qatar residents living abroad may be funded by HMC to travel to Qatar for donation to their resident relative.

2.5.1 Not an incentive. Last month, the wife of a Nepalese labourer resident in Qatar was flown to Doha to donate to her husband. She received no payment of any kind, but was provided with flights and accommodation. This effectively removed the financial barrier to her altruistic donation.

2.5.2 *But isn't a free trip to visit your husband in Doha an incentive?* Only if you think spending your visit at the hospital having your kidney removed to save your husband's life is an incentive without which you wouldn't donate. The woman in this case flew home after ten days to be with her children.

2.5.3 How are these prospective related nonresident LD evaluated?

2.5.3.1 They are screened medically in their home country by a nephrologist in consultation with HMC. A checklist is used to ensure relevant information is collected, which is reviewed by the Donor evaluation committee in Qatar. If approved, they are supplied with temporary visa and travel funding if they need it.

2.5.3.2 Of note, the visa provided for this travel does not enable donors to obtain employment or residency rights of any kind in Qatar. They are brought in under sponsorship of HMC and no one can offer them a job until they have departed the country.

2.6 LD are honoured with a medal at a ceremony, and have been, on occasion, flown back to Doha for celebratory events surrounding organ donation.

2.6.1 Not an incentive. The medal offers no material advantage with no apparent commercial value. The possibility of receiving a free trip to Doha in the future is consistent with the sporadic opportunities given to donors in many countries to attend conferences, public events, campaigns and so on. It is not a guaranteed benefit.

3 Are families of potential deceased donors offered anything that might represent an incentive inconsistent with the Declaration?

3.1 A family member of a DD may be provided with transport to the hospital and/or flights to Doha and accommodation where non-resident, so as to attend their relative in the ICU.

3.1.1 Not an incentive. Where there are barriers (economic or visa related) preventing a relative attending a dying patient in the ICU (irrespective of brain death or fixed pupils etc), the hospital's social work program – initiated usually by nurses attending patients – may provide such support to relatives. It is an advantage to which all patient families have a right.

3.1.2 However, the active engagement of a donor coordinator may help to facilitate access to such travel support for potential donor families (especially with respect to bureaucratic hurdles involved in obtaining visas). This support is not conditional on consent to donation. Further, it may remove a barrier to donation by providing relatives with an opportunity to attend and discuss possibility of donation with hospital staff, enhancing autonomy in the decision.

3.1.3 Of note, at least one family that was offered this recently apparently declined. It's possible that the offer helps to foster trust by providing an opportunity to "check" on a relative prior to deciding on donation. It's unlikely to act as an incentive given members of poor families may face additional barriers to travel such as their own employment responsibilities and/or need to care for dependents.

3.2 Any costs of burial of the DD, or transfer home of the expatriate DD coffin, are covered.

3.2.1 Not an incentive. All expatriate workers are covered by Qatari laws governing disposition of bodies following death, with visa sponsors responsible for securing the right to decent burial or repatriation of the coffin. At no time is a payment for these services made to DD families.

3.3 DD families will receive welfare support where needed.

3.3.1 Not an incentive. All potential DD brought to the attention of the donor team will be evaluated by the hospital's social work program with respect to their economic status and welfare needs of dependents (and all deaths within the hospital are automatically evaluated by the SWP).

3.3.2 The donation team takes responsibility for facilitating interactions with the SWP if required following identification of welfare needs. Economic support is paid on a monthly basis to the families in need, according to the predetermined benefit tables of the Social Work Department, regardless of whether consent for donation is obtained.

3.3.3 The Organ Donation Centre adopts responsibility for the implementation of the social welfare program, including by following up recipients of support on an annual basis to review needs.

3.3.4 2 out of a total 15 consents to deceased donation received since Jan 2011, received welfare. An additional four consents were in progress, but all revealed commercialism and thus consent was invalidated for all. One of these four cases had been evaluated as needing welfare support, and this was delivered as per the HMC social work program. The potential donor in question - despite being an excellent candidate for organ procurement- was rejected by the Donor Centre, as family members had tried to negotiate a "higher" level of economic support when consenting for donation.

3.3.5 Potential DD families are assured of access to welfare support regardless of whether they choose to donate, with a number of refused consent families receiving support.

3.3.6 No lump sum payments are provided to families, and it is made explicit that access to welfare support does not represent a "price" for donated organs, hence the Donation Centre strives to ensure any support is not superior to the income previously being provided by the deceased, even where the SWP "benefits book" sets a higher level support. Payments may cease, for example, when a widow remarries or the economic status of the family improves.

3.3.7 The evaluation of prospective DD families made by the SWP is assisted through information obtained from the donation team, embassy, and sponsor of the potential DD worker, but the evaluation remains the independent responsibility of the HMC SWP. The Donation Centre nevertheless takes personal responsibility for reviewing documentation so as to maintain the integrity of the donation program, looking for anything suggestive of commercialism in donation decision-making or practice.

3.3.8 ***So what is the Organ Donation Fund?*** This charity provides support for the activities of the Organ Donation Centre in education and promotion of donation, for example. It may also be used to provide for "extraordinary" costs such as travel costs for expatriate related live donors coming to Doha.

3.4 Families of DD receive a medal of honour

3.4.1 See justification of same above for living donors.

4 Who gets the organs?

4.1 Does the non-citizen population (which represents the majority of the potential donor pool, and includes those more at risk of becoming a potential donor through workplace accidents) **receive a fair share of donated organs?**

4.1.1 All those waitlisted for transplantation are governed by the same allocation criteria without regard for citizenship status or other discriminatory factors. A look at the waitlist shows patients from all over the world, with Bangladeshis listed above Qataris where the latter have registered later etc. I'm sure a report on this fascinating data will be made by Riadh and his colleagues in the course of their pending report about the update and progress of the DDA as per the resolution of the DICG meeting in April.

4.2 **What about getting wait listed?**

4.2.1 All those who present to HMC with end stage renal failure in need of dialysis are provided with care with costs covered by the Institute of Social Development as required (see background information on Page 1). All those eligible for transplantation are waitlisted without regard for citizenship or economic status.

4.2.2 Since January 2011, Of the 20 transplanted using DD organs in Doha, 3 went to Qatari citizens and 17 to non-citizen residents.

5 While building an equitable and effective program of donation and transplantation in Qatar, what efforts are being made to curb transplant tourism by Qataris given the ongoing shortage of organs for transplantation?

5.1 As all Qatari patients resident in Qatar with organ failure are managed by HMC, it is possible to know the precise number of patients who go abroad and usually the countries to which they have travelled.

5.1.1 The Ministry of Health appears to have been very cooperative with efforts to develop ethical systems of donation and transplantation within Qatar while discouraging the ethically and medically hazardous practice of travel abroad for commercial transplantation.

5.1.2 The number of transplant tourists from Qatar has fallen by 87% since 2008, and the preferred destination of such tourists has shifted from the majority going to China to the US and the UK.

5.1.3 As noted in the summary, the majority of Qatari citizens (73%) in need of transplantation are now choosing to be waitlisted in Doha, indicating that trust has developed in the domestic program.

6 Some further comments

6.1 The Donor Registry and approach to consent

The success of the recent Ramadan campaign is impressive, with more than 19 000 individuals from at least 88 different nationalities now registered since its launch a year ago. The approach to obtaining consent for registrants is interesting in that it appears to be quite a personalized, labour intensive process. Information sessions led by community leaders have targeted various ethnic, religious and cultural groups, with members of the donation team and those assisting for the campaign, communicating information in the language of prospective registrants (clearly a huge task given the 88 different nationalities) and in a manner consistent with relevant cultures and religions. Each consent form signature requires verification by two witnesses with IDs of these and the registrant scanned and filed.

Promotional messages are conveyed in news bulletins, newspapers, via the radio and television and cinema advertisements.

6.2 Messages of the donation promotion campaign

Prospective registrants are encouraged to join by appealing to their sense of community, reminding them of their healthcare entitlements, that they and even their nonresident family members may be assisted to access care, including transplantation, and that they and their families are in safe hands when engaging with the healthcare system. The idea of reciprocity, of giving back to this community if the occasion to become a deceased arises, is emphasised as a potential community duty or obligation. Appeal is also made to the religious virtues inherent in saving lives

6.3 Keys to success

The progress made here Doha appears to be a testament to the commitment at all levels to implement ethical policy and practice. The former program of offering financial incentives was a failure. Although it may be tempting to suggest that financial resources are largely responsible for the emerging success of the new program, I think it is better attributed to the ethos of the program. This reflects the approach implemented so successfully by Professor Rizvi and his colleagues at the SIUT in Pakistan – if the poor are enfranchised in donation and transplantation, with equitable access and recognition of the value of their donations, they will trust in the system and be willing to donate without the use of financial incentives. Similarly, wealthier citizens are increasingly registering for donation and seeking to donate to relatives as the value of donation gains social recognition.

Of course, financial support for the program is essential, and the involvement and support of various charities such as Qatar Charity, Qatar Red Crescent and even Qatar Airways makes this program economically feasible for Hamad Medical Corporation. Engagement at a broad level with various social institutions also doubtless helps to reinforce the notion of donation and transplantation as a community oriented system and a societal responsibility.

Nevertheless, the program here faces some unique challenges, in that the majority of the population is likely to turn over every three years or so, as expatriate workers return home. Developing a sustained culture of donation and developing societal awareness and understanding of deceased donation in this setting is likely to require novel strategies to avoid reinventing the wheel, as it were, every few years, as well as to engage with the extended expatriate families of residents.

The Doha Model that is emerging is cognizant of these challenges and is developing into a comprehensive, multifaceted strategic approach on a number of levels. Underpinning this drive towards self-sufficiency is an ethos of care within the Organ Donation Centre, with the primary concern the well being of donors, their families and transplant patients.