NATIONAL BIOETHICS COMMITTEE

DRAFT MINUTES OF THE MEETING OF THE NATIONAL BIOETHICS COMMITTEE (NBC) 13 November 2014

A meeting of the National Bioethics Committee (NBC) was held on 13 November 2014 at Serena Hotel, Quetta. Due to non-availability of the Secretary Health, Dr Aasim Ahmad, Member National Bioethics Committee & Chair Research Ethics Committee (REC), chaired the meeting.

Following Members attended the meeting:

- 1. Prof. Dr. Farhat Moazam, Professor & Chairperson, Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and transplant, Karachi.
- 2. Prof. Dr. Aasim Ahmad, Dean and Chief Nephrologist, Kidney Centre, Karachi
- 3. Dr. Dad Muhammad (Representative), Director General Health Services, Health Department, Government of Baluchistan, Quetta.
- 4. Dr Saleem Memon (Representative) Director General Health Services, Health Department, Government of Sindh.
- 5. Maj. Gen Abdul Khaliq Naveed (Representative) DGMS (IS)/Surgeon General, Pakistan Army. Medical Directorate, General Head Quarters, Rawalpindi.
- 1. Prof. Naqibullah Achakzai (Representative) President CPSP), Quetta
- 2. Prof. Dr. Abdul Razzaq Sabir, Vice Chancellor, University of Turbat (Baluchistan), Mekran Division, Baluchistan.
- 3. Prof. Dr. Mukhtar (Representative), Director General (Health), Health Department, Government of AJK, Muzzafarabad.
- 4. Dr. Aamir Mustafa Jafarey, Associate Professor Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and Transplantation, Karachi.
- 5. Dr. Farah Qadir, Head of Department Behavioral Sciences, Fatima Jinnah Women University, Rawalpindi
- 6. Dr. Ghulam Nabi Qazi, World Health Organization, Islamabad.

7. Dr. Muhammad Arif Munir (Representative) Executive Director PMRC and Member/Secretary NBC. Pakistan Medical Research Council, off Constitution Avenue, Sector G-5/2, Islamabad.

Following members could not attend the meeting due to their prior commitments:

- 1. President, Pakistan Medical and Dental Council (PMDC)/Representative, Mauve Area, G-10/4, Islamabad
- 2. President, Supreme Court Bar Association, Supreme Court Building, Islamabad
- 3. Director General Health Services, Health Department, Government of Khyber Pakhtun Khwa.
- 4. Director Health Services, Federally Administered Tribal Areas (FATA)
- 5. Director Health Services, Health Department, Government of Gilgit Baltistan
- 6. Dr Tariq Mehmood Mian, President, Pakistan Association of Family Physicians
- 7. Dr. Huma Qureshi, Executive Director PMRC and Member/Secretary NBC. Pakistan Medical Research Council, off Constitution Avenue, Sector G-5/2, Islamabad.
- 8. Dr. Farid Khan, 68/1 Khyban-e-Mahafiz, Phase 6, DHA, Karachi
- 9. Dr. Mahjabeen Khan, Assistant Professor, Research and Development, Dow University of Health Sciences, Karachi
- 10. Prof. Dr Munir Akhtar Saleemi, Professor of Social and Preventive Pediatrics, Sir Ganga Ram Hospital, Lahore
- 11. Dr. Abdul Majeed Akhtar, Representative Nominee, Director General Health, Health Department, Government of Punjab, DG Office, 6 Cooper Road, Lahore.
- 12. Mrs. Nighat Ejaz Durrani, Registrar, Nursing Council, Islamabad
- 13. Prof. Dr. Asmatullah, Associate Professor (IRI), International Islamic University, Shah Faisal Mosque, Islamabad. P.O Box 1035, GPO, Islamabad.
- 14. Prof. Dr Hafizullah, Vice Chancellor, Khyber Medical University, Peshawar.
- 15. Prof. Dr Zafar Hayat, Khyber University Head of Department Medicine. Khyber Teaching Hospital, Peshawar

The meeting started with recitation from the Holy Quran. Dr. Muhammad Arif Munir welcomed the participants of the meeting. He informed the members that as decided in one of the meetings last year, in the absence of the Chair, the meeting shall be presided by one of the Chair of the two sub committees of NBC, therefore Dr Aasim Ahmad was requested to Chair the meeting.

Dr Aasim Ahmad appreciated the members who came all the way to attend the meeting. He however, expressed his disappointment at the absence of any member or provincial representative from KPK and FATA as well as Representative of PM & DC. Once again the Chair stressed that it is the responsibility of members to attend all NBC meetings so as to maintain continuity in actions.

After the introduction of the members, the Chair asked the Representative of the Member/Secretary NBC to start the proceedings of the meeting.

Agenda item 1: Approval of minutes of the last NBC meeting held on 07 August 2014.

Dr Muhammad Arif Munir informed the house that minutes were circulated to all members and any corrections that had been suggested were incorporated. It was again pointed out that only a handful of members acknowledged receipt of minutes sent to them, and re-emphasized that a brief note to this effect was important and also courteous. The members were requested to approve the minutes.

Decision: Minutes were approved.

Agenda item 2: Progress in establishing PBCs

Dr. Muhammad Arif Munir updated the members on the decisions of the last NBC meeting held in Peshawar on 07 August 2014 and the actions taken. He informed the house that as per decision of the last NBC meeting all Provincial DGs or their nominees were asked to establish PBC in their Provinces and inform the NBC Secretariat about the progress. The chair then invited each provincial representative to provide a progress report.

2.2. **Progress on PBC Baluchistan**: Dr Dad Muhammad representing Director General Health, Baluchistan informed the members that Baluchistan has constituted the provincial Bioethics Committee Balochistan. The composition of the Committee has been forwarded to the Secretary Health, Government of Balochistan for approval and notification which is expected in next few days. In reply to a question by Dr Farhat Moazam regarding formulation of TORs of the PBC Dr Dad Muhammad said that they have developed these after consulting the TORs of PBC Punjab. Dr Farhat Moazam stated that the TORs of PBCs were extremely important and that correct composition of members and functioning of the committee were required. As an example, the list of names of Punjab PBC members sent to NBC was restricted to individuals from Lahore, and the Baluchistan PBC included no one from outside Quetta. Both committees also consisted almost entirely of physicians with none from non-medical sciences. She suggested the possibility of including a couple of provincial NBC members into PBCs to allow better coordination between the two committees. In response Dr Dad Muhammad said that amendments in TORs can be done if so required. The Chair suggested that the composition of the PBC should not be restricted to members from Quetta only, but should also have representation from other districts in Balochistan for wider participation and ownership. This was agreed by all the Members.

Decision: Dr Dad Muhammad will share the TORs of PBC Balochistan with NBC and addition of members from other districts will be considered at a later stage. He will also inform the NBC Secretariat when the PBC is "notified" by the Secretary Health.

2.5. Progress on PBC Sindh: The representative of Director General Health Services, Sindh, Dr. Saleem Memon, informed the house that they are still in the process of constituting the PBC Sindh. He requested the Chair for a special briefing from NBC members stationed at Karachi to the Sindh DG and other members identified by the DG Health Sindh. NBC could consider organizing an ethics workshop for them along the lines of the one to be run in Quetta over the next two days.

Decision: The Chair agreed to the proposal. Dr Saleem Memon will inform Dr Aasim Ahmad and Dr Farhat Moazam regarding the dates for briefing and would also identify the persons to be sensitized from various medical institutions/universities.

2.6. **Progress on PBC AJK:** The representative of Director General Health, AJK, Dr. Muhammad Mukhtar gave a comprehensive Power Point Presentation on the formulation of Regional and Divisional Bioethics Committees. He informed the house that they have plans for the following Bioethics Committees:

A. Regional **B**ioethics Committee (would be equivalent to PBC)

B. Divisional Bioethics Committees (Divisional Bioethics Committees included AJK Medical College (Muzzafarabad); MBBS Medical College (Mirpur) and Poonch Medical College (RawlaKot).

Dr Moazam observed that the three divisional committees are connected to medical colleges/universities and such committees are generally termed Institutional Review Committees. The suggestion was well taken and Dr Mukhtar agreed to consider renaming the divisional committees as such.

Dr Mukhtar also presented detailed composition of each level of committee. The House appreciated the efforts of Dr Mukhtar. Dr Moazam suggested including representatives from social sciences, perhaps a psychologist/psychiatrist, in these committees. Dr Mukhtar agreed and said he would do so. Regarding TORs he was of the opinion that common TORs should be developed for all provinces and AJK. The Chair Dr Aasim Ahmad said that he and Dr. Moazam have been discussing that NBC should develop standard TORs for use by PBCs and hopefully this will be undertaken in the near future. He explained that the basic TOR principles would be the same, however the provinces could tailor their TOR to suit their local contexts but staying within established parameters. He further mentioned that even NBC TORs, constituted over 12 years ago, need to be revisited and revamped.

Decision: NBC will develop standard TORs for PBCs laying out general Principles and circulate to all provinces. Dr Mukhtar will share with NBC Secretariat once the committees are formally notified

2.7. Due to the absence of any representative from Punjab, there was no PBC progress report from the province

2.8. Due to the absence of any representative from Khyber Puktoonkhwa, there was no PBC progress report from the province.

Agenda Item 3: Briefing on Research Ethics Committee.

Members of REC

- 1. Dr. Aasim Ahmad (Chair)
- 2. Dr. Ismat Ullah
- 3. Dr. Huma Qureshi
- 4. Dr. Munir Saleemi
- 5. Dr. Aamir Jafarey
- 6. Dr. Mahjabeen Khan

Dr. Aasim Ahmad gave detailed briefing on the progress regarding Research Ethics Committee (REC). He discussed the process of projects evaluation and review and gave feedback on the projects received in 2014. He informed the house that to date 26 projects have been received out of which 21 have been reviewed by REC and approved while, 5 projects are in the process of review and ethical approval. He further deliberated that once the project is reviewed and comments of the members are received, these are coalesced and then sent to the principal investigators/researchers to respond within one month time. If they do not respond in 4 months' time their files are closed and they need to resubmit their applications.

He also shared with the house about the fee structure for reviewing the projects by the REC. Dr Aasim further updated the Members that TORs of Research Ethics Committee have been revised and shared with the Members for their feedback, the project review form (ERC Application Form) and guidance document have also been revised and updated. Dr Aasim categorically mentioned that the current membership of REC is very low and more members need to be added. He requested the members to volunteer for being the REC members and send their CVs for selection. Dr Aasim also said that the newly drafted REC TORs will be shared with the NBC Members in the next NBC meeting.

During the discussion Dr. Aamir Jafarey pointed out that even from the small REC only a very few members were "active" reviewers in the true sense and had to carry the major load. Dr Moazam said that the REC could be expanded perhaps with people identified from each province for project review and their names sent to NBC. Dr Aamir Jafarey seconded the suggestion from

Dr Moazam and said that members may also be Co-opted from other institutions that have some training in project ethics review, and that this has been done successfully by the HCEC for relevant tasks. He also suggested that, as in this NBC meeting, the REC should also have a scheduled session following future NBC meetings. Dr Moazam agreed and added that each NBC meeting, in addition to the REC session should also be followed by a bioethics workshop. This was unanimously agreed by all members.

Dr Najeebullah Achakzai, Representative CPSP, raised his concern on the fee charged by the NBC under two categories i.e. Expedited and Routine review. He was of the opinion that since for expedited review the Principal investigator has to pay higher amount of fee as compared to routine review therefore, people who could not pay the expedited fee may have their projects delayed. Dr Aasim Ahmad explained to the Members that expedited review requires solid justification and every project do not merit expedited review. He said that on many occasions the students are given waiver in the fee despite the fact that their request is justified for expedited review. The members appreciated the efforts of Dr Aasim Ahmad for revising the TORs and other documents pertaining to REC. Dr Moazam requested the provinces to let NBC know if, in addition to NBC meeting connected workshops, they are interested in bioethics workshops to train the local people. All interested provinces should forward such requests in writing to the NBC Secretariat.

Decisions:

Dr Aasim Ahmad will present the final draft of TORs developed for Research Ethics Committee along with updated ERC Application form and Guidance notes in the next NBC Meeting.

Agenda Item 4: Report on HCEC progress. Dr Moazam, Chair Health Care Ethics Committee (HCEC), presented progress on HCEC activities and provided some general information due to new members present in the room. Dr Moazam informed the members that the objectives of Health Care Ethics Committees (of NBC and PBCs) should be to focus on fostering ethics education and capacity building, and to serve in an advisory capacity to institutions and associations such as the PMDC. HCECs do not possess regulatory or enforcement authority.

The HCEC of NBC has been working for several months on preparing guidelines to help national medical and dental colleges introduce bioethics into the undergraduate curriculums. The current composition of HCEC is as follows:

- 1. Dr Farhat Moazam (Chairperson)
- 2. Dr Aasim Ahmad (Member)
- 3. Dr Aamir Jafarey (Member)
- 4. Dr. Farid Khan (Member)
- 5. Dr Syed Haroon Ahmed (Co-opted retired NBC Member)
- 6. Mr Shaukat Ali Jawed (Co-opted retired NBC Member)
- 7. Dr Abdul Ghani (Co-opted Member, Baluchistan)
- 8. Dr Asma Humayun (Co-opted Member, Islamabad)
- 9. Dr Saima Pervez Iqbal (Co-opted Member, Islamabad)

Dr Farhat Moazam stated that HCEC members and co-opted members have been selected for their relevant expertise. Unfortunately most HCEC members are from Karachi but despite repeated requests there have been no volunteers from the other provinces, and there remains a need to have provincial representation.

Dr. Jafarey then gave a comprehensive PP presentation providing an overview of Guidelines for Bioethics Curriculum for Undergraduate Medical/Dental Students which HCEC has developed over the last year and a half. He and Dr. Moazam went over and clarified salient features of the Guidelines document draft electronic copies of which had been circulated to NBC members previously (hard copies provided in the meeting). While the PMDC Code of Ethics calls for strategies for the dissemination of bioethics information to medical and dental colleges no steps have been taken so far. The HCEC Guidelines document is meant to address this. Dr. Moazam reiterated that these Guidelines can only be enforced and implemented through PM&DC backing and gazette notification and distribution to colleges, but despite multiple requests and letters to appropriate officials, no PMDC representative has ever attended any of the HCEC meetings. Dr. Jafarey described to members the accompanying Hand Book that has been developed and provides essential teaching tools such as reading material, articles, relevant references and links, case reports and videos etc.

Upon the issue of continued absence of representation of PM&DC, Prof Dr Mukhtar Ahmad suggested that Maj. Gen (R) Abdul Khaliq Naveed who is an active member of the PMDC Board of Directors, present in the meeting, be co-opted as the PM&DC Representative for HCEC. Maj. Gen.(R) Abdul Khaliq Naveed agreed with the suggestion and, when requested by Dr. Moazam, said he would bring this up with the PMDC Board and try to attend the next HCEC meeting scheduled for January 2015 in CBEC, Karachi.

The house appreciated the effort. NBC members were requested to review the Guidelines document draft again and email any suggestions they may have to the NBC Secretariat.

Following suggestions were put forward by the Members for consideration by HCEC members in their next meeting:

- 1. The Guidelines should also address ethical issues pertaining to animals in addition to humans
- 2. Consider adding to Guidelines objectives measures teaching students how to "Counsel" patients
- 3. Bioethics workshops by HCEC should also be conducted in other provinces.

Decisions:

- 1. Any further suggestions on Guidelines for Bioethics Curriculum for Undergraduate Medical/Dental Students developed by HCEC to be sent via email to NBC
- 2. Hand Book once finalized will be shared with NBC members.
- 3. Maj. Gen ® Abdul Khaliq Naveed agreed to act as a focal person of PM&DC and will attend the January 2015 HCEC meeting in Karachi
- 4. The Provinces/institutions interested in organizing research and clinical ethics educational workshops should contact NBC and HCEC will be happy to help organize these.

Agenda Item 5: AOB.

- Following a discussion, it was agreed that venue of next NBC meeting and a two day ethics workshop will be Azad Jammu and Kashmir in the first or second week of March 2015.
- 2. The TOR of NBC and its two sub-committees need to be revisited and an appropriate process identified to do so. The TORs for PBCs should be standardized accordingly.
- NBC Members were requested to volunteer to help with the proposed review of TORs for NBC and PBC via email to NBC Secretariat
- Dr Farah Qadir recommended that junior faculty be included as members in order to have them as properly functional units in the Provincial Bioethics Committees and subcommittees
- Dr Aasim Ahmad stressed that the scope of bioethics committees and selection should be beyond the Medical Colleges. Dentists and non-medics should also be invited as members of NBC, PBCs, HECE, and REC.
- 6. Regarding nomination of Chair Provincial Bioethics Committees, Chair said that it is up to the provincial bioethics committees to decide their Chairperson.

Decision:

The next NBC meeting will be held in between 1-14th March 2015 at AJK. But district polio campaign days should be kept in consideration while finalizing the dates.

The meeting ended with vote of thanks by Dr. Aasim Ahmad.

Dr Aasim Ahmad Chair REC 30th Dec. 2014

Secretary Ministry of NHSR&C