PAKISTAN MEDICAL RESEARCH COUNCIL

National Bioethics Committee Secretariat

DRAFT MINUTES OF THE MEETING OF THE NATIONAL BIOETHICS COMMITTEE (NBC) 07 August 2014

A meeting of the National Bioethics Committee (NBC) was held on 07 August 2014 at Pearl Continental Hotel, Peshawar. Due to the absence of the Secretary Health, Dr Farhat Moazam, Member National Bioethics Committee & Chair Health Care Ethics Committee, chaired the meeting. Following persons attended the meeting:

- 1. Dr. Farhat Moazam, Professor & Chairperson, Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and transplant, Karachi.
- 2. Dr. Abdul Majid Akhtar, Representative Nominee, Director General Health, Health Department, Government of Punjab, DG Office, 6 Cooper Road, Lahore.
- 3. Prof. Dr. Mukhtar (Representative), Director General (Health), Health Department, Government of AJK, Muzzafarabad.
- 4. Dr. Dad Muhammad (Representative), Director General (Health), Health Department, Government of Baluchistan, Quetta.
- 5. Prof. Dr. Abdul Razzaq Sabir, Vice Chancellor, University of Turbat (Baluchistan), Mekran Division, Baluchistan.
- 6. Dr Pervez Kamal Khan, Director Health Services, Federally Administered Tribal Areas (FATA)
- 7. Prof. Dr Hafizullah, Vice Chancellor, Khyber Medical University, Peshawar.
- 8. Dr. Shaad Muhammad, Director Academics, Khyber Medical University, Peshawar.
- 9. Mrs. Fauzia Mushtaq (Representative) Registrar, Pakistan Nursing Council, Near National Institute of Health, Chak Shahzad, Islamabad.
- 10. Prof. Dr Mumtaz Marwat (Representative) President CPSP), Principal Army Medical College, Rawalpindi.

- 11. Dr. Huma Qureshi, Executive Director PMRC and Member/Secretary NBC. Pakistan Medical Research Council, off Constitution Avenue, Sector G-5/2, Islamabad.
- 12. Prof. Dr. Asmatullah, Associate Professor (IRI), International Islamic University, Shah Faisal Mosque, Islamabad. P.O Box 1035, GPO, Islamabad.
- 13. Dr. Syed Muhammad Mursaleen, World Health Organization, Islamabad.
- 14. Dr. Muhammad Arif Munir, Focal Person, NBC Secretariat, 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), Mauve Area, G-10/4, Islamabad
- 2. DGMS (IS)/Surgeon General, Pakistan Army. Medical Directorate, General Head Quarters, Rawalpindi.
- 3. President, Supreme Court Bar Association, Supreme Court Building, Islamabad
- 4. Director General Health Services, Health Department, Government of Sindh.
- 5. Director General Health Services, Health Department, Government of Khyber Pakhtun Khwa.
- 6. Director Health Services, Health Department, Government of Gilgit Baltistan
- 7. President, Pakistan Association of Family Physicians
- 8. Dr. Farah Qadir, Head of Department Behavioral Sciences, Fatima Jinnah Women University, Rawalpindi
- 9. Dr. Farid Khan, 68/1 Khyban-e-Mahafiz, Phase 6, DHA, Karachi
- 10. Prof Dr Aasim Ahmad, Dean and Chief Nephrologist, Kidney Centre, Karachi
- 11. Dr Mahjabeen Khan, Assistant Professor, Research and Development, Dow University of Health Sciences, Karachi
- 12. Dr. Aamir Mustafa Jafarey, Associate Professor Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and Transplantation, Karachi.

13. Prof. Dr Munir Akhtar Saleemi, Professor of Social and Preventive Pediatrics, Sir

Ganga Ram Hospital, Lahore

The meeting started with recitation from the Holy Quran. Dr. Huma Qureshi welcomed

the participants of the meeting. She 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 one of the two sub committees of NBC, therefore Dr Farhat Moazam was

requested to Chair the meeting.

Dr Farhat Moazam appreciated the members who came all the way to attend the meeting.

She however, expressed her disappointment at the absence of any member or provincial

representative from Sindh, and as well as that of the Director General or his

representative from KPK. She however, thanked Dr. Shaad Muhammad and Dr.

Hafeezullah (when he arrived) of KMU for taking the time to attend the NBC meeting on

invitation. She stressed that it is the responsibility of members to attend all NBC

meetings so as to maintain continuity in actions. She reiterated that members who are

unable to attend should inform the NBC Secretariat well ahead of time. Per NBC policy,

failure to attend 3 consecutive meetings without information could lead to cancellation of

membership.

After the introduction of the members, the Chair asked the Member/Secretary NBC to

start the proceedings of the meeting.

Agenda item 1: Approval of minutes of the last NBC meeting held on 10th March. 2013.

Dr Huma Qureshi, Member/Secretary NBC informed that the minutes were circulated to

all members and corrections suggested by the members were incorporated. The members

were requested to approve the minutes.

Decision: Minutes were approved.

Agenda item 2: Progress of NBC

Due to the presence of several first time attendees, Dr. Huma Qureshi gave a briefing

about the National Bioethics Committee, its aims and objectives, composition and

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functions of its sub committee's i.e. Health Care Ethics Committee (HCEC) and the Research Ethics Committee (REC).

Following this she updated the members on the current status and steps taken by the Provinces towards establishment of Provincial Bioethics Committees. 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.

2.1. **Progress on PBC Punjab:** Dr Abdul Majid Akhtar from Punjab informed that they have established the PBC in March and notified its members. He further told the house that training of the PBC members was done by the NBC in collaboration with the Directorate General Health Services in Lahore on 17th March 2014. Dr Farhat Moazam congratulated Punjab on the establishment of Provincial Bioethics Committee and stressed that all PBCs should constitute health care and research ethics sub-committees. She pointed out that "training" of PBC members was an ongoing process not possible in one meeting, and that they should organize future workshops with NBC help for members in both research and clinical ethics areas.

Questions and general discussion on PBCS followed and helped to clarify confusion about their functioning among those present. Dr. Moazam requested that the secretariat circulate the TORs to all members to facilitate them in formulation of their own provincial bioethics committees. The composition of PBC Punjab should also be circulated to all provinces and she advised that PBCS should maintain minutes of each meeting and forward a copy to the NBC secretariat for record.

Dr Zafar Hayat, NBC MEMBER from KPK stated that in his opinion, due to mushrooming of new medical colleges NBC should widen its scope in regulating their activities and practices and curtailing unethical practices. He also suggested establishing district level bioethics committees rather than maintaining an approach that worked from up to down. Dr Farhat Moazam explained that NBC and PBCs are not regulatory bodies but function in an advisory role to the government and for helping in educating and sensitizing institutions and researchers to follow ethical guidelines. She said that whereas the NBC formulates guidelines for ethical practice it is the role of the Pakistan Medical &

Dental Council and similar bodies to regulate medical practices, the functions of the two bodies are expected to come together via PM&DC and CPSP representatives who are NBC members. She quoted as example physician pharma ethical interaction guidelines developed by NBC which PM&DC then endorsed and distributed as gazetted document to all medical colleges.

2.2. **Progress on PBC Baluchistan**: Dr Dad Muhammad representing Director General Health, Baluchistan informed the members that Baluchistan has had a notified committee of 06 members for quite a while but they have not held a meeting yet. He said that following the discussions in NBC today, they shall induct more members in the PBC and circulate the new composition of PBC to all NBC members. Dr. Sabir suggested, and everyone agreed, that PBC members should include a mix of relevant individuals with different backgrounds instead of only physicians.

It was decided that the first PBC meeting and training should coincide with the ethics workshop which HCEC and Dr Farhat Moazam are organizing in Quetta in November 2014. NBC members also agreed that the next NBC meeting be held concomitant with the ethics workshop/PBC meeting in Quetta. Dr. Moazam asked NBC members to ensure that they keep the week of November 11-16 free for the 3 day events in Quetta. they will be informed of the confirmed NBC meeting date within the next few days. Dr Mursaleen suggested that Divisional Directors may also be invited to the workshop to which all members agreed.

2.3. **Progress on PBC KPK**: Dr Huma Qureshi informed the members that it was decided in the December 2013 meeting that Provincial Committee of KPK shall also work for FATA and GB. A letter was written on 2nd Jan 2014 to Health Secretary KPK with copy to Dr Farhat Moazam for establishment of PBC. Later Dr Farhat Moazam discussed the formulation of PBC with Prof. Dr Hafeezullah, Vice Chancellor, Khyber Medical University, KPK who agreed to facilitate the process. She stated that a letter was also written by the NBC Secretariat to Dr Hafizullah to facilitate the health department in the formulation of provincial bioethics committee but KPK has not yet formed a PBC. She said that the Secretariat has requested Dr Hafizullah to take the Director General

Health, KPK on board and include him as the Chair PBC as is the case in other Provinces.

Dr Hafeezullah informed NBC members that Khyber Medical University already has a very active oversight bioethics committee at the university level together with research ethics committees in different institutions under KMU. DGs are generally too busy to participate in such activities. Dr. Moazam clarified that PBCs are at the provincial level are in no way or form meant to replace existing committees like those in KMU. These, in her opinion, and based on her own long involvement with KMU in bioethics education, are already functioning very well.

Nevertheless, provinces are required to establish PBCs with Director General Health as the "official" chair, but in her opinion the effectiveness of any PBC would depend on its members. She requested Dr. Hafizullah that he and others like him in KMU with experience and background in ethics could, as members of the PBC of KPK, help to make it among the strongest while ensuring that it has representation from other districts in KPK. She asked Dr. Hafizullah to help NBC by contacting the Director General Health KPK to try and get the PBC formed in KPK, and perhaps provide a progress report in the next NBC meeting.

- 2.4. **Progress on PBC FATA.** The Director Health Services FATA, Dr Kamal Pervez Khan, told the house that not much progress has been made on the establishment of an independent PBC for FATA. He stated that FATA would be happy to work with Dr Hafizullah in a combined KPK PBC. The two agreed to meet and report the outcome to NBC in its next meeting.
- 2.5. **Progress on PBC Sindh:** For Sindh, the Member Secretary informed that Dr. Aasim Ahmed volunteered to approach DUHS, LNH and other institutions to assist in the formulation of PBC. To facilitate Dr Aasim, PMRC wrote letters to the concerned hospitals with a copy Dr Aasim Ahmad. Letters were also sent to Secretary Health and special Secretary along with multiple telephone calls to expedite the nomination. Each time special Secretary assured that they will do the needful but there is not much progress. In fact in this meeting Sindh was the only province that had failed to send a representative. Dr Farhat Moazam said that the secretariat should write letters to DG

Health, Sindh and Dr Saleem Memon who was present in the Lahore NBC meeting, expressing NBC's disappointment and concern at the lack of interest and progress in establishing a PBC for Sindh.

2.6. **Progress on PBC AJK:** The representative of Director General Health, AJK, Dr Mukhtar informed the house that he is working to formulate Regional Bioethics Committee in AJK. He pointed out that to make this committee functional they need training for Institutional Bioethics Committees in the medical colleges. He requested NBC for arranging training workshop in Muzzafarabad and also requested that one of the subsequent NBC meetings may be held in Muzzafarabad. NBC members were in agreement and the chair stated that the march 2015 NBC meeting could perhaps be held in Muzzafarabad. she said that NBC will make it a point to meet in different provinces to be more inclusive and to help develop a sense of ownership among NBC members.

Decisions:

- 1. All Provincial DG Health, or their focal persons present in the NBC meeting, will make every effort to establish Provincial Bioethics Committees in their provinces and inform the NBC Secretariat about their progress. They will be expected to provide a report on their progress and activities in the next NBC meeting.
- 2. NBC Secretariat will send letters to DGHS Sindh and Dr Saleem Memon who attended the last NBC meeting in Lahore (on behalf of DG health) expressing concern about Sindh non-representation in today's meeting and requesting a progress report on PBC, Sindh.
- 3. Members from KPK and GB shall meet to discuss a joint PBC. Dr.Hafizullah will try to help move the PBC forward by speaking with the DG Health KPK.
- 4. NBC Secretariat to circulate TORs and composition of PBC Punjab to all provinces and to NBC members to facilitate them in formulation of their Provincial Bioethics Committees.
- 5. NBC members will keep the week of November 11-16 free for the next NBC meeting in Quetta. The confirmed meeting date will be emailed to them within the next few days.

- 2.7. **Printing of Stem cell and physician- pharma guidelines**: Dr Huma told the house that Stem Cell Guidelines have been printed and were given to all members who were present in the meeting and they are being distributed to institutions who are doing stem cell therapy. Physician-pharma guidelines, will be printed sometimes next week and would be made available to all members and distributed to all Medical Institutions.
- 2.8. **NBC** website: Dr Huma informed the house that the NBC website hosted at Riphah University was hacked in September, 2013 and they could not restore it therefore, it has been loaded on COMSATS website with address www.nbcpakistan.org.pk Members asked her to log on to demonstrate the website but this was not possible due to poor availability of internet connection in the hotel. They were requested to access it later and send back any comments they had.

Agenda Item 3: **Progress on Research Ethics Committee**. D Huma Qureshi updated the house on the progress regarding Research Ethics Committee (REC). She discussed the process of projects evaluation and review and gave feedback on the projects received in 2014. She said that to date 15 projects have been received out of which 10 have been reviewed by REC and approved while, 5 projects are in the process of review and ethical approval. She further updated the house on the following events/progress made by the REC:

- Dr Aasim Ahmad has taken over as the Chair of REC following completion of tenure by Dr Bhutta
- The ToRs of REC needed revision, so they were developed & shared with REC members, agreed and finally revised and uploaded on web
- The project review form and the guidance document have also been revised and uploaded
- They shall be pilot tested for 6 months to get feedback from REC members and if needed revised accordingly

Decisions:

- 1. List of current REC members needs to be circulated to all NBC members.
- 2. Letters should be written to all Principal Investigators of the projects submitted for ethical review asking them to submit a copy of the final report of their completed project.
- 3. Dr Huma Qureshi will report to the next NBC meeting regarding the progress of projects reviewed and how many have been completed to date.

Agenda Item 4: **Report on HCEC progress**. Dr Moazam, Chair Health Care Ethics Committee (HCEC), presented progress on HCEC activities and some general information due to new members present in the room. Dr Moazam informed the members that Health Care Ethics Committee is a Sub-committee focusing on education and guidelines for clinical ethics. Following is the composition of HCEC:

- 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)
- 8. Dr Asma Humayun (Co-opted Member)
- 9. Dr Saima Pervez Iqbal (Co-opted Member)

Since its constitution in December 2012, HCEC has met 6 times in CBEC, Karachi, and the next meeting is scheduled for this August on the 12th. HCEC members and co-opted members have been selected for their expertise and to try to expand representation beyond Karachi.

Dr. Moazam said that currently the HCEC has two major aims - 1) Initiating and expanding capacity building in clinical and healthcare ethics in the provinces through workshops and seminars that include these aspects in addition to research ethics, 2) Developing broad guidelines to help faculty introduce basic ethics education in the undergraduate curriculum of dental and medical colleges in Pakistan and to be implemented through PMDC assistance. The HCEC guidelines document will include a "Hand Book" with resource materials to help teachers in organizing sessions on ethics. She said that it is hoped that at the next HCEC meeting members will be able to finalize the guidelines/Hand book, and she could perhaps make a half hour presentation on it in the next NBC meeting. She agreed with the members' suggestion that the document be circulated ahead of the meeting to allow better discussion.

She stated that a continuing problem HCEC faces has been the complete absence of any representative from PM&DC (also assigned as HCEC member) despite repeated letters, emails, and phone calls to PM&DC officials (some as recent as last month). The ethics guidelines document can only be enforced through PM&DC backing and gazette notification and distribution to medical colleges. Dr Hafizullah offered to approach President PM&DC to nominate someone from PM&DC to attend the HCEC meeting in Karachi. He requested, and was provided, copies of Dr. Moazam's correspondence with members of PM&DC, and said he would try and see if a PM&DC member could attend the HCEC meeting this month.

Decisions:

- Dr Farhat Moazam will circulate the Guidelines developed by HCEC to all NBC Members before the Quetta Workshop. The agenda will include time for discussion.
- 2. NBC Secretariat will e-mail to Dr. Hafizullah the copies of NBC Secretariat letters sent to PM&DC at the close of Peshawar meeting.
- 3. 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.

1. Dr Moazam congratulated NBC for the third consecutive meeting held as

scheduled and reiterated the importance of agreeing on the date and venue for the

next NBC meeting before leaving. Following a discussion, it was agreed that

venue of next NBC meetings will be Quetta during the week of 10-15 November

2014 followed by 02 days Ethics Workshop for PBC Members and others from

health related institutions in Baluchistan.

2. It was also decided that the subsequent March 2015 NBC meeting will be held in

Muzzafarabad, AJK.

3. Dr Moazam suggested that the agenda item on CROs (which was not discussed

today) could include a brief informational presentation by Dr Aamir Jafarey in the

next NBC meeting.

Decisions:

1. The next NBC meeting will be held in between 11-16 November 2014 at

Quetta. Dr Farhat Moazam will intimate the final dates to the NBC

Secretariat.

2. Dr Aamir Jafery will give 10 minutes presentation in the next NBC

meeting regarding CROs.

The meeting ended with vote of thanks by Dr. Moazam.

Dr Farhat Moazam Chairperson HCEC

03 April 2014

Secretary Ministry of NHSR&C

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