#### PAKISTAN MEDICAL RESEARCH COUNCIL

#### **National Bioethics Committee Secretariat**

# MINUTES OF THE MEETING OF THE NATIONAL BIOETHICS COMMITTEE (NBC) 10 MARCH 2014

A meeting of the National Bioethics Committee (NBC) was held on 10 March 2014 at Hotel SunFort, Lahore. Due to prior commitment, Secretary ministry of NHSR&C could not attend, therefore Dr Farhat Moazam, Member National Bioethics Committee & Chair Health Care Ethics Committee, was requested to chair the meeting. Following Members attended the meeting:

- 1. Dr. Zahid Parvez Khan, Director General Health, Health Department, Government of Punjab, DG Office, 6 Cooper Road, Lahore.
- 2. Dr. Haroon Jahangir Khan, Director Health and Focal point Provincial Bioethics Committee, DG Office 6 Cooper Road, Lahore.
- 3. Dr. Abdur Rehman (Representative), Director General (Health), Health Department, Government of KPK, Peshawar.
- 4. Dr. Saleem Memon (Representative), Director General (Health), Health Department, Government of Sindh, Karachi.
- 5. Dr. Dr. Farooq Azam Jan, (Representative), Director General (Health), Health Department, Government of Baluchistan, Quetta.
- 6. Mrs. Nighat Ejaz Durani, Registrar, Pakistan Nursing Council, Near National Institute of Health, Chak Shahzad, Islamabad.
- 7. Maj. Gen. Abdul Khaliq Naveed (Nominee DGMS –IS/Surgeon General/, Pak Army or his nominee), Dean Army Medical College, Abid Majeed Road, Rawalpindi Cantt. Rawalpindi.
- 8. Prof. Maj. Gen. Salman Ali (Nominee, President CPSP), Principal Army Medical College, Rawalpindi.
- 9. Prof. Dr. Zulfiqar Bhutta, Division Head, Women and Child Health Department of Paediatrics, the Aga Khan University, Stadium Road, Karachi -74800.

- 10. Dr. Syed Haroon Ahmed, Director, Psycho Social Centre, 11-13 Hilal-e-Ahmer House, Clifton, Karachi.
- 11. Dr. Maqbool H. Jafary, Cardiologist, House No. 114B, Johar Town, Lahore.
- 12. Mr. Shaukat Ali Jawaid, Editor Inchief, Pakistan Journal of Medical Sciences & Pulse International, Room No.522, 5<sup>th</sup> Floor, Panorama Centre, Building No.2, Raja Ghuzanffar Ali Road, Sadder, Karachi.
- 13. Prof. Dr. Asim Ahmed, Professor / Chief Nephrologist, The Kidney Centre, 197/9 Rafiqui Shaheed Road, Karachi-7553.
- 14. Dr. Huma Qureshi, Executive Director PMRC and Member/Secretary NBC. Pakistan Medical Research Council, off Constitution Avenue, Sector G-5/2, Islamabad.
- 15. Prof. Dr. Asmatullah, Associate Professor (IRI), International Islamic University, Shah Faisal Mosque, Islamabad. P.O Box 1035, GPO, Islamabad.
- 16. Prof. Dr. Abdul Razzaq Sabir, Director, Balochistan Study Centre, University of Balochistan, Quetta.
- 17. Dr. Muhammad Mursaleen, World Health Organization, Islamabad.
- 18. Dr. Munir A. Saleemi, Department of Social and Preventive Pediatric, FJMC/Sir Ganga Ram Hospital, Lahore.
- 19. Dr. Amir Mustafa Jaffery, Associate Professor/Surgeon, Centre for Biomedical Ethics and Culture, Sindh Institute of Urology and Transplant, Karachi.
- 20. Dr. Farhat Moazam, Professor & Chairperson, Centre of Biomedical Ethics and Culture, Sindh Institute of Urology and transplant, Karachi.
- 21. Dr. Tariq Mehmood Mian, Dr. Tariq Mehmood Mian, President, Pakistan Association of Family Physicians, 196-Atta Turk Block, New Garden Town, Lahore-54600, Pakistan.
- 22. Dr. M. Arif Munir, Focal Point, NBC secretariat, Pakistan Medical Research Council, off Constitution Avenue, Sector G-5/2, Islamabad

The meeting started with recitation from the Holy Quran. Dr. Moazam welcomed the participants and the newly selected NBC members and expressed her appreciation at the presence of representatives from all four provinces. She stressed that it is the responsibility of members to attend NBC meetings regularly (something that has not

always happened in the past) as effectiveness of NBC required this continuity, and requested that assignments and tasks entrusted be completed and the Committee kept updated on the progress. She informed the new members that in case anyone is unable to attend the NBC meeting it is her/his responsibility to 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 28<sup>th</sup> Dec. 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

Presentation on progress of NBC was made by Dr Huma Qureshi Member/Secretary NBC. She announced the names of the new NBC members and welcomed them to the Committee. (List of new members is attached at Annexure I.) She then reviewed the current status and steps taken towards establishment of Provincial Bioethics Committees (PBCs), and informed the house that as per decision of the last NBC meeting the NBC secretariat has completed the following tasks:

2.1. Progress on Provincial Bioethics Committees (KPK, FATA and GB): She informed the members that it was decided in the December 2013 NBC meeting that Provincial Committee of KPK shall also work for FATA and GB. A letter was written on 2<sup>nd</sup> Jan 2014 to Health Secretary KPK with copy to Dr Farhat Moazam for establishment of PBC but since then there appears to have been no further progress regarding this matter. Dr. Bhutta said that much work on the establishment of institutional bioethics committees has already been done in KPK and there are well trained persons in bioethics in the provinces

whose experiences can be utilized for the formulation of Provincial Bioethics Committees.

Dr Farhat Moazam informed the house that she has discussed the issue of formulation of PBC with Prof. Dr Hafeezullah, Vice Chancellor, Khyber Medical University, KPK and he has agreed to facilitate the process by contacting the DG Health KPK and she hoped that they will take appropriate action and move forward. She agreed with Dr. Bhutta that in many ways KPK is ahead of other provinces in its bioethics capacity. The Center of Biomedical Ethics and Culture, SIUT has been running workshops and seminars for KMU faculty, staff and trainees in Peshawar twice a year for over 4 years, and many in the province have already initiated Institutional Bioethics Committees in their institutions. The representative of Director General Health (KPK) Dr Abdur Rahman informed the house that the delay in formation of Provincial Bioethics Committees in KP has been mainly due to the frequent transfers of the Provincial Health Secretaries and Director General Health. He promised that every effort will be made to establish Provincial Bioethics Committee in KPK on priority basis.

- 2.2. Progress on Provincial Bioethics Committees Sindh: For Sindh. Member Secretary informed the house that Dr. Aasim Ahmed volunteered to approach DUHS, LNH and other institutions to assist in the formulation of PBC. To facilitate Dr Aasim for approaching the concerned institutions, PMRC has written letters to the concerned quarters with a copy Dr Aasim Ahmad. The representative Director General Health, Sindh, assured their full cooperation to Dr Aasim Ahmad for the establishment of Provincial Bioethics Committees Sindh. Dr. Moazam requested that Dr. Arif also provide to the representative who is representing the DG in the meeting today, relevant documents for the formation of the Provincial Bioethics Committees in Sindh so that he can follow through on this with the DG.
- 2.3. Progress on Provincial Bioethics Committees Baluchistan: Member Secretary Dr Huma informed the Members that NBC Secretariat has sent a letter to the Secretary Health and Director General Health, Baluchistan regarding the functioning of the

Provincial Bioethics Committees, also informing them that Dr Farhat Moazam and the Health Care Ethics Committee of NBC have volunteered to organize an ethics training workshop in Quetta. The representative of DG Baluchistan stated that they are in the process of constituting the Provincial Bioethics Committees and would inform the progress by the end March 2014. Dr Farhat Moazam informed the house that Baluchistan already has a PBC in place with the DG as chair and 7 other members including Mr. Abdul Ghani who is also a co-opted member of Heath Care Ethics Committee. However her information is that due to recent events connected to DG position there has been no movement in getting the Provincial Bioethics Committees functioning. This has also delayed Health Care Ethics Committee plans for the Quetta ethics workshop which may now have to be considered for sometime in the latter half of 2014. The Baluchistan representative promised to follow up on the matter with the DG.

2.4. Progress on Provincial Bioethics Committees Punjab: Dr Huma Qureshi informed the members that Punjab has not yet established provincial bioethics committee. She said that Maj.Gen Muhammad Aslam Vice Chancellor, University of Health Sciences, Lahore has very kindly agreed to collaborate with the Punjab Health department, regarding the establishment of Provincial Bioethics Committee. The Director General Health Punjab, who is an ex-officio Member of NBC, highlighted the importance of National Bioethics Committee, and assured the house that he would formulate PBC Punjab by the end march 2014. He nominated Dr Haroon Jahangir Khan, Director Health Services, Punjab as Focal person for the Provincial Bioethics Committee. Dr Farhat Moazam thanked the DG (who had to leave soon after for an emergency) and explained that the Punjab PBC, like others, should include two sub committees' one dealing with research ethics issues (REC) and the other with ethics pertaining to health care (HCEC). DG agreed to the suggestions and asked Dr Haroon Jahangir Khan (the nominated focal person for Provincial Bioethics Committees Punjab) to get the process done on priority.

Decision: 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 on priority basis and the NBC Secretariat about the progress. Secretariat will also monitor the progress with the Provinces.

## A report will be provided to NBC members by DGs/their representatives regarding progress at the next NBC meeting.

2.5. PMDC representation: Dr Huma informed the house that for the representation of PM&DC in the NBC and Health Care Ethics Committee meetings, the NBC Secretariat has sent a number of letters the last one being sent on 8<sup>th</sup> Jan 2014. There has been no response from PM&DC, and committee members expressed their grave concern, once again, at this unfortunate lack of interest in an important matter. Dr Farhat Moazam reported that in view of no response from Dr. Amjad the current PMDC registrar, despite repeated attempts, she had recently spoken by phone about this issue with Dr Shaista Faisal, the deputy registrar of PMDC. Dr Shaista seemed interested in the undergraduate ethics guidelines being prepared by HCEC and said that she is in fact the focal person for curriculum development in PMDC. She expressed her willingness to attend the next Health Care Ethics Committee meeting if needed. Dr. Moazam will write again to Dr. Amjad, this time with a copy to Dr. Shaista, about the necessity of PMDC representation in the Health Care Ethics Committee meeting.

## Decision: Dr Moazam will keep NBC abreast with any further progress made with Dr. Shaista Faisal in reference with the HCEC

- 2.6. NBC Budget: As per decision of the last NBC Meeting, Dr Huma Qureshi, Member Secretary, presented the report on yearly budget and expenditures of NBC. The members inquired about PMRC budget for NBC, to which she informed them that an amount of 3 million has been allocated for various NBC and its committee's activities. The budget lapses once the financial year ends. However a second source of substantial funds for NBC is generated from fees charged by the NBC research ethics subcommittee to review and approve research proposals, a sum which rolls over to the next year if left unspent.
- 2.7. National surveys not seeking ethical clearance: It was decided in the last NBC meeting that National surveys like DIHS, Economic survey, Census should also take NBC clearance prior to launching the Surveys. Dr Huma Informed the house that the Director General, Ministry of National Health Services, regulation and Coordination has

already sent instructions to the departments conducting the said national surveys and Census to comply with the instructions of NBC and get their projects ethically cleared before being implemented. The members showed their satisfaction on this important step.

Following the presentation of a summary by Dr. Huma about the number of ethics proposals reviewed/approved/rejected, Dr. Razzaq Sabir of Balochistan suggested that information should also be provided about how many approved proposals were actually completed. This was agreed by all.

Decision: Information about how many proposals were completed will be included in future reports presented by the research ethics review sub-committee to NBC

2.8. Retaining NBC members beyond 2 tenures. Dr Huma informed the house that it was decided in the last NBC that the tenure of members is 4 years extendable to another 4 years. It was pointed out that there is no clear policy regarding further extension in tenure but a year of extension has been offered to a few. (The list of outgoing members who have completed 9 years of tenure is attached at annexure II.) Dr. Moazam stated that it was important for members to consider this matter and come up with a transparent policy to be followed in the future.

After a discussion in which some members from Sindh and KPK supported retaining members beyond fixed tenure due to their "experience" and for their past contributions, the consensus reached was that it was more important to bring in "new blood" that could help rejuvenate NBC and also involve and train young people. Those retiring could only be "co-opted" for a limited length of time by subcommittees, in exceptional cases, if considered critical to an ongoing activity. Dr. Moazam requested that she would like Dr. Haroon and Mr. Shaukat to serve as "co-opted" members of the HCEC which was at a critical juncture in formulating undergraduate ethics guidelines and for which their input was essential for another few months this year.

#### **Decisions:**

- i) NBC members completing 9 (8+1) years of service will not be given an extension. In exceptional cases, a retiring member may be "co-opted" by NBC sub-committees for limited period of time if judged irreplaceable for an ongoing NBC activity.
- ii) The request by Dr. Moazam for co-opting Dr. Haroon and Mr. Shaukat in the HCEC until completion of the ethics guidelines for undergraduates was approved by NBC. Both members agreed to comply with her request.
- 2.9. Printing of Stem cell and physician-pharma guidelines: Dr Huma told the house that for the printing of Physician-pharma and stem cell guidelines, PMRC/ NBC Secretariat has already uploaded tender on PPRA Website. Dr Moazam asked PMRC to give a deadline for the printing and was informed that it would take about 3 months. The deadline agreed on was June 15 of this year. She stated this it would be the responsibility of the NBC Secretariat to inform NBC members via email if the deadline would need to be extended.

Decision: PMRC to proceed with the printing as per deadline (June 15) and any change in the schedule will be brought to the notice of the NBC.

Agenda Item 3: Report on Health Care Ethics Committee progress with ethical guidelines. 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. Since its constitution in December 2012, HCEC has met frequently with 06 meetings held in CBEC, Karachi so far. The next HCEC meeting is tentatively scheduled for August 12 this year following the end of Ramzan. Co-opted HCEC members (to expand representation beyond Karachi and also for their expertise) include Dr Aamir Jafarey (who is now regularized as new NBC member), Mr. Abdul Ghani from Baluchistan (member of PBC), Dr. Saima, family physician from Islamabad, and Dr. Asma Humayun, psychiatrist from Islamabad.

Dr. Moazam said that currently this group has two major aims - 1) Initiating and expanding capacity building in clinical and healthcare ethics in the provinces through workshops and seminars. She stated that all NBC workshops should include education in

clinical ethics together with research ethics. The Quetta workshop, now delayed, being organized by HCEC was to have been among the first in this effort. 2) Developing broad guidelines to help faculty introduce ethics in the undergraduate curriculum of dental and medical colleges in Pakistan, and to be implemented through PMDC assistance. The guidelines document will include a "Hand Book" with resource materials to help teachers in organizing sessions on ethics. Dr Moazam reiterated the importance of a PMDC representative being present in the HCEC during discussions and will see if Dr. Shaista Faisal can be convinced to attend the next HCEC meeting. Once the ethics guidelines and hand book documents are completed, they will be shared with the larger NBC group.

Dr Aamir Jafarey suggested that NBC prepare a time schedule of ethics workshops and circulate this among NBC members well ahead of time to allow people to reschedule their commitments and be available for teaching. Dr Huma said that once the training dates are agreed by the Provincial Health Departments a schedule will be prepared and shared with the members. It was pointed out to her that a better approach would be for the NBC to decide on workshop dates based on availability of NBC facilitator date suited them. This matter was left unresolved.

Dr. Huma informed members that the PMRC is conducting a Training Workshop on the Establishment of Institutional Bioethics Committees in collaboration with University of Health Sciences, at Lahore on 17<sup>th</sup> March 2014. She invited the DG Health Punjab and the focal person PBC Punjab for participation in the training. The DG health assured that they would participate in the said workshop. Dr Mursaleen, representative WR Pakistan (WHO) supported Dr Huma for conducting provincial workshops and ensured that he could assist us in getting some technical assistance and support from WHO.

In the end Dr. Huma invited members completing their tenure and retiring to express their experiences and views during their stay with NBC.

Dr Zulfiqar A Bhutta, Member NBC/Chair Research Ethics committees, while expressing his experiences highlighted the historical inception of National Bioethics Committee. He mentioned about the notification issued by the Ministry of Health to all medical institutions in the country regarding obtaining ethical clearance from NBC before launching the research projects. He said that though the formulation of NBC as a gazette

notified body of the Ministry of Health has been a great success, much remains to be done at the provincial level including their trainings. He further added that one thing which is still missing is the code of conduct regarding formulation of provincial bioethics committees and the institutional bioethics review committees. Dr Bhutta welcomed the new NBC members and emphasized that fresh blood is highly required for the continuation of NBC and PBCs. He emphasized that Research Ethics committee should be more vibrant and the young people should start thinking as to how this can be accentuated. For the outgoing members Dr Bhutta suggested that they should continue to volunteer their support to NBC and PBCs. At the end he thanked the NBC for their cooperation and support.

Mr. Shaukat Ali Jawaid welcomed the new members and said that lots of efforts have been put by the then Executive Director PMRC, Dr Tasleem Akhtar in the formulation of NBC. He also named the then Secretary Health Mr. Ejaz Rahim and the Director General Health Maj. Gen. Muhammad Aslam for their guidance and staunch support in the establishment of NBC. He said that his voluntary support would always be available to NBC. He also emphasized the need for the formulation of provincial bioethics committees.

Dr Syed Haroon Ahmed welcomed the new members and highlighted the important role of NBC in Research and Ethics. He highlighted the important role of REC and congratulated Dr Farhat on being selected as the Chair of HCEC. Dr Haroon however, said that there is a need to generate more funds for NBC. He pointed out that currently the resource generation is through REC only. He asked Mr. Shaukat Ali Jawaid whether the funds from the Pharmaceutical Industry research fund can be allocated to NBC. In response Dr Huma informed the house that the research fund from pharmaceutical industry rests with the Ministry of Finance and that the TORs of this account is so tough that it is very difficult to get the money. There was no further discussion on this proposal and neither any further direction was given by the Chair NBC.

Dr Maqbool Jaffery welcomed the new members. He said that in-spite of all the odds the NBC has put in lots of hard work to survive and function He congratulated the committee on carrying forward the tremendous task and offered his volunteer services as and when

required. He also mentioned that he has now settled in Lahore and can contribute in the

formulation of Provincial Bioethics Committees and for lectures during trainings.

The new NBC members thanked the Chair upon their selection as members NBC and

ensured the committee that they would discharge their responsibilities to the best of their

knowledge and experience.

Agenda Item 4: Next Chair Research Ethics committee (REC). Dr Zulfiqar Bhutta

proposed the name of Dr Aasim Ahmed, Member NBC to be the Chair Research Ethics

Committee. This was unanimously approved. Dr. Moazam requested that he will need to

reformulate the committee with the retirement of Dr. Bhutta and Mr. Shaukat, and should

provide a report in the next NBC meeting.

**Decisions:** 

i) Dr Aasim Ahmad as new Chair Research Ethics Committee will reformulate the

new REC as soon as possible, and ii) He will provide progress report of REC

activities at the next NBC meeting.

**Agenda Item 5:** AOB.

1. On her inquiry, Dr. Moazam was told that the NBC website which had been

hacked was not yet sorted out. She requested that the matter be resolved and a

report to this effect be provided at the next NBC meeting.

Decision: NBC members will be provided a report on the website in the next

meeting

2. Dr Moazam reiterated the importance of agreeing on the date and venue for the

next NBC meeting before leaving to allow members to adjust their schedules

accordingly and be ready to attend. Following a discussion, it was decided that

venue of meetings should be rotated among provinces and the next meeting

should be held in Peshawar. It was decided that the next NBC meeting will be

held on 8<sup>th</sup> August 2014 in Peshawar.

Decision: The next NBC meeting will be held in August 2014 at Peshawar.

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In the end Dr Huma Qureshi presented the Shields to retiring NBC members. The meeting ended with vote of thanks by Dr. Moazam.

Secretary Ministry of NHSR&C

### Annexure-I

### LIST OF NEW MEMBERS

Dr Aamir Jafarey	CBEC, Sindh	Academics	Replacement
Dr Mahjabeen Khan	DUHS, Sindh	Bio scientist	Replacement
Dr Zafar Hayat	KMU, KPK	Academics	Replacement
Dr Munir A Saleemi	FJMC, Punjab	Bio scientist	Replacement
Dr Farah Qadir	FJWU, Punjab	Social Scientist	Replacement
Abdul Razzaq Sabir	TU, Balochistan	Human Right	Replacement
Dr Tariq Mehmood Mian	PAFP, Punjab	General practitioner	Replacement
Ms Nighat Durrani	Registrar, PNC	Nurse	Ex-Officio

#### **Annexure-II**

# LIST OF MEMBERS WHO HAVE COMPLETED THEIR TENURE WITH NBC

- 1. Prof. Dr Zulfiqar A Bhutta
- 2. Dr. Maqbool H. Jafary
- 3. Prof. Dr. Syed Haroon Ahmed
- 4. Prof. Dr Anis Ahmed
- 5. Mr. Shaukat Ali Jawaid
- 6. Dr Anwar Nasim (Retd)
- 7. Dr Anwar Aziz (Retd)
- 8. Dr Saeed ul Majeed
- 9. Dr Muhammad Amin (Late)