Access to Medicines Research Network On-line Consultation: Summary of Responses

I. BACKGROUND

The UK Department for International Development is proposing, subject to an assessment of potential demand, to establish a global Access to Medicines Research Network (ATM RN). The proposed **purpose** of the ATM RN would be to provide a flexible and responsive mechanism to generate policy-oriented research on issues affecting poor people's access to essential medicines.

Proposals for an ATM RN are at an early stage. To understand the demand for such a network and to inform its design, an on-line public consultation was held from 1-30 June 2008 to gain views from a wide range of stakeholders on a number of key issues.

A total of 153 people submitted their views through the on-line consultation. This paper provides a summary of those views. It is organised around the 8 sections of the consultation survey. Quantitative data is aggregated and presented in annex 1. Qualitative data from free text responses in integrated into summary below. The paper concludes by outlining next steps for a decision on whether to launch an ATM RN and possible designs and timelines if the proposal goes ahead.

II. OUTCOMES FROM THE PUBLIC CONSULTATION

Section 1: Information about Respondents

A total of 153 people submitted their views through the on-line consultation. Just over one third of respondents (35%) were from academic organisations. A further 14% of respondents worked in charitable organisations. The remaining 51% of respondents worked in a variety of organisational settings: government/public sector (10%), research networks (9%), consultancy organisations (7%), think tanks (3%), bilateral or multilateral donor organisations (2%), private foundations (1%) and other private sector organisations (4%). 11% noted 'other' and 3% of respondents had no organisational affiliation.

The geographical location of respondents was extremely diverse, with responses coming from 41 different countries. 54% of the responses came from OECD countries, 18% were from Africa, 22% from Asia and 4% from the Middle East and 3% Latin America.

Section 2: Access to Medicines – Research Priorities

The Existing Evidence Base

To identify research priorities, the consultation survey posed two questions regarding the existing evidence base in the field of access to medicines. The first sought to establish the areas where a good evidence base exists. The second focused on identifying topics where significant gaps exist. The responses to these two questions were somewhat contradictory. In seven out of sixteen topics, responses indicated that there was **both** a good evidence

base and significant gaps in the evidence base.[1] For example, a similar number of respondents felt there was a strong evidence base as those that felt there were gaps with respect to the quality of pharmaceuticals in the public sector, drug promotion practices, the impact of global health initiatives and in market structure analysis in the pharmaceutical sector. However, there were several topics where the number of responses indicating a gap in the evidence base far outstrips those indicating a good evidence base. These topics include: the quality of pharmaceuticals in the private and faith-based sector, pricing of pharmaceuticals in the private and faith-based sector, sustainable financing for equitable access to essential medicines, human resources for the delivery of equitable access to medicines, approaches to combating leakage of pharmaceuticals through the supply chain and demand-side barriers to equitable access to essential medicines.

Ensuring Developing Country Priorities Inform ATM Priority Research Areas

The consultation survey invited proposals on how developing country priorities could inform the ATM priority research areas. Responses focused on: i) the stakeholders to be consulted; ii) the channels through which these stakeholders could be consulted and priorities identified.

Box 1: Stakeholders to be consulted

- National Ministry of Health
- Other government departments e.g. drug regulatory agencies
- Health insurance agencies
- Regional and local government departments
- Public and private health service providers
- Academic institutions, including medical schools
- Research institutes and research networks e.g. INRUD
- Scientific and ethical review committees
- International and national civil society organisations, e.g. HAI, MSF, Ecumenical Pharmaceutical Network, consumer associations
- Trade unions and professional associations
- Consultancy organisations e.g. MSH
- International development agencies e.g. WHO, World Bank, UNCTAD,UNDP, South Centre Centre

The proposed range of stakeholders to be consulted is wide (see Box 1). Respondents have highlighted the need to consult at the local level, including health providers and service users, in addition to the national and international levels. They have also highlighted the need to consult civil society. Some civil society organisations may be particularly tuned into research needs at a national level, as monitoring research gaps forms part of their work e.g. Health Action International regional offices. Some respondents emphasised the need for a national research agenda to be developed by policy-makers and researchers working together. This collaboration would ensure that research undertaken stemmed from an analysis of real problems faced in providing access to medicines within a given context. Others added to this that to translate research into practice a consensus between policy-makers, academics/researchers, implementing agencies, local politicians and donor agencies was needed. Regular consultation involving these stakeholders was proposed as an opportunity to debate key issues and generate an acceptable research agenda.

[1] With a difference of less than 10 in the number of respondents considering that there is a good evidence base and the number considering that there are significant gaps in the evidence base.

Box 2: Channels for consultation and priority identification

- Literature reviews to map existing knowledge
- Sessions at international meetings e.g. the Global Health Research Forum
- Identification of key informants and eliciting sequential rounds of comments
- Focus group discussions with selected specialists and other stakeholders
- Structured consultation with stakeholders
- Surveys, conducted either virtually, or at the national and local levels
- Formation of an active network to participate in brainstorming meetings
- Virtual discussion groups e.g. E-Drug
- Medicines Transparency Alliance structures at national and international levels
- Establish national multi-stakeholder research committees, which draft research strategy
- Identify country co-ordinators with a remit of identifying priority research areas

The range of channels for consultation with these stakeholders to identify priority research areas was equally as diverse (See Box 2). The need to draw upon existing resources and meetings was emphasised. For example, the Global Health Research Forum would be a key international event, at which participants could be invited to discuss research priorities. However, to make the sessions productive, it is important that participants prepare in advance of them. Circulating consultation documents ahead of a meeting and asking participants to prepare inputs for the meeting are examples of ways in which the productivity of such meetings can be maximised. Whilst the use of electronic and virtual networks was identified as a useful means of consulting with stakeholders, it was noted that some stakeholders in developing countries may have difficulties participating in such networks. A balance between virtual consultation and consultation in person would therefore seem to be required.

Section 3: Commissioning Research through the Access to Medicines Research Network

The majority of respondents supported the proposed approach to commissioning research through the ATM research network. However, a number of important concerns were highlighted:

a) Governance structures of the ATM research network

To ensure transparent and effective operations, the governance structures of the ATM research network need to be further elaborated. Specifically, this would include: clarifying the respective roles of the Management Organisation and the Advisory Committee; defining who is accountable to whom; defining the process and criteria for the selection of the Management Organisation and the members of the Advisory Committee and making this public; including in governance structures representatives of all major stakeholders, including public health policy-makers, civil society, the private sector, developing country governments and DFID; defining the process and criteria for the identification of research priorities and selection of research providers and making this public.

b) Finding the right Management Organisation

The success of the ATM research network will, to a large extent, depend on the effectiveness and creativity of the Management Organisation. It is important that the Management Organisation's full terms of reference are

spelled out in detail, as well as essential competencies. These are likely to include: technical expertise, skills in communication, knowledge management and capacity development, capability to identify a varied set of research institutions and being multi-lingual and multi-cultural. It is also essential for the Management Organisation to be seen as neutral in what is a contentious policy area.

c) The possibility of duplication of efforts
Some respondents felt that the ATM research network risked duplicating existing initiatives, especially the work of WHO.

d) Top-down approach
There were concerns that the approach was too top-down and that this could result in the needs of developing countries not being met and the network having limited impact at the national level. More democratic and decentralised structures were proposed, particularly for the identification of research priorities.

Respondents proposed varied ideas of how these challenges might be overcome. Some of these are captured in Box 3.

Box 3: Proposed Responses to Challenges in the ATM Research Network Approach to Commissioning Research

Governance Structures
- Review the experience of the Interstate Panel on Climate Change to inform the governance structures, especially the role of the Advisory Committee
- The membership of the Advisory Committee and how the Management Organisation is funded is in the public domain
- Advisory Committee members are selected by stakeholders
- Publicise the ATM research network well to allow diverse institutions and groups to participate
- Develop a code of good practice for the research network and its members
- Put in place a grievance process for research providers to make appeals if necessary
- Capacity building support may be required to enable some southern based organisations to fully participate
- Decisions on funding for research should be approved by an advisory panel that includes recognised and respected academic researchers
- Involve a broad stakeholder representation in the governance structures

Management Organisation
- Follow a transparent process in the selection of the Management Organisation, including a clear set of ToRs, clear and public criteria for the selection

Duplication of Efforts
- Host the Management Organisation within an existing institution already engaged in ATM research e.g. WHO

Top-down Approach
- Identify a host organisation to facilitate the network in each country
- Decentralise the research prioritisation process to ensure that specific country needs are prioritised
- Involve stakeholders involved in MeTA national stakeholder fora in the identification of research priorities and questions
- Put in place a feedback mechanism that allows network researchers to submit ideas for new research topics that fall within the purview of ATM RN's mission

Other
- May be more valuable to offer DCs support in carrying out research, perhaps led by institutions and experts from developed countries.
- Support long-term research partnerships instead of short-term engagements
- Regularly evaluate the uptake, use and value added of research activities

Section 4: Data Repository

Nearly 96% of respondents felt that an access to medicines data repository would be useful. Almost all respondents with published research reported being willing to make it available through an ATM data repository. In addition, 53% of respondents were willing to make raw datasets available via an ATM data repository, the majority of whom would do so within 6-12 months of data generation, manipulation and analysis. Almost a third of respondents stated that they had no datasets to make available.

Respondents raised a number of reasons why a data repository would be useful. These included the potential to pull together currently dispersed data; providing a resource that could prevent duplication of research and data gathering efforts; providing a resource that can help identify gaps in the evidence base and help prioritise new research; the potential to simplify access to data and analysis, particularly for developing countries; and the potential for some quality assurance of data and research. Respondents identified a range of different types of information that could be stored including; medicines datasets (e.g. household data); both positive and negative project evaluations (i.e. learn what did and what didn't work); methodologies and; grey literature. Some respondents suggested that a wiki based function could be included to make information easily accessible to a wide range of users.

Respondents also raised a number of cautions or issues that plans for a repository would need to address. These included the need for open access to data; how to support users with limited internet access; the need for active management of and *long-term* commitment to a repository; linked to this, the option of housing a repository at a permanent organisation, such as WHO; the need to avoid duplication of existing resources, how link to them and how to add value based on actual demand for information and analysis (there needs to be clarity about which audiences a repository would be aimed at).

Section 5: Translating Research Findings into Use

There was a remarkable amount of consensus among respondents about critical actions to ensure research findings inform policy and practice in developing countries.

Respondents felt that a clear demand for the proposed research among policy-makers was of critical importance. A feeling among policy-makers that research is being done to support them, is applicable to their situation and is of good quality were all considered essential. To achieve this level of ownership, respondents proposed full involvement of policy-makers throughout the research cycle, from the identification of the research problem to data analysis and finally, agreement and execution of practical follow-up steps to enact some of the research's policy recommendations. The Center for Global Development working group model, which focuses on collaborative analysis of key global health topics, was highlighted as one possible approach.

Following this theme of local ownership, respondents recommended that, as far as possible, research projects should be managed by developing country institutions (however, one respondent suggested that developing country researchers need to do more to build stronger local networks to influence policy makers and the media).

Research undertaken could be integrally linked to policy development, for example, it could evaluate policy outcomes or policy development processes. Irrespective of the issue to be investigated, it was proposed that the research question should be framed from a policy perspective. In addition, it was suggested that attempts should be made to understand in advance of the research what types of policy research and questions are likely are more likely to deliver successful outcomes. Finally, a number of respondents highlighted the need for research to be practical.

For research to be useful to policy-makers, inclusion of policy recommendations in research outputs was considered essential. The policy recommendations must be made available in easily digestible formats e.g. as policy briefs or technical papers and must present solutions rather than obstacles. If possible cost-benefit studies of policy recommendations should be included. The use of case studies in research outputs was also considered valuable. Language was highlighted as a critical issue in policy recommendations. The language used should be easily accessible. Translation of policy recommendations into languages other than English would also enhance their dissemination potential.

Respondents suggested that a robust communication/dissemination strategy of research outcomes was an essential part of any research proposal. One respondent cited, as an example of good practice, the new DFID Research Strategy commitment of allocating 30% of DFID research funding to making research available and accessible. Whilst the use of the internet and research journals were noted as opportunities for disseminating research findings, respondents generally felt that they were inadequate to lead to changes in policy and practice. Instead, more interactive post-research activities were proposed to help policy-makers understand the implications of the research recommendations and decide next steps for implementing recommendations e.g. action-oriented meetings that guide the mapping of research results into an action plan, policy workshops and in-country briefings. In some cases, research policy recommendations can be far-reaching and governments and other stakeholders may require technical support to take them forward. Respondents felt that the provision of such support was important. Ensuring a range of development agencies are aware of the research and engaged in discussion of its results may help facilitate this.

Finally, respondents felt it important to consistently monitor the policy impact of research. It was proposed that the experience of USAID's MEASURE evaluation project, which focuses on data driven decision-making, might provide some useful insights in this area.

Section 6: Supporting Southern Institutions to participate in the Access to Medicines Research Network

The limited national funding for research was considered the most critical impediment, which could prevent southern organisations from actively participating in research on access to medicines, with nearly 55% of respondents citing this as a barrier. Local resources were also noted as being important for long-term sustainability. Experience in designing high quality research and research proposals was viewed as the second most important constraint, with nearly 34% of respondents citing this as a barrier. Approximately 20% of respondents considered that each of the following were real constraints to southern organisation participation: experience with a diverse set of research methodologies, experience of drawing evidence-based conclusions from research findings, low domestic regard for research at the national level and experience of writing policy-oriented products. Financial management skills were considered the least important barrier, with only 4.5% citing this as an issue. Only 2% of respondents felt that there were no barriers to southern organisation participation.

Several respondents noted that a lack of demand for research by policy makers is an important cause of low levels of domestic funding. The potential for local vested interest groups (both local and international) to block research into sensitive issues was raised by 3 respondents. A number of respondents commented on the relationship between northern and southern institutions, noting that northern partners are usually designated as principle investigators and often smother southern partners. Conversely, one respondent suggested that southern institutions have not been as quick to develop multi-disciplinary teams as their northern counterparts, putting them at a disadvantage in bidding for research in complex fields. Several people pointed out that there are high quality researchers and departments in a number of countries, but that they quickly become over stretched by multiple commissions. Better funding for individual projects could take some institutional pressure off well regarded researchers by making revenue less dependent of volume of studies.

To address these barriers, 46% of respondents felt funds earmarked for small research projects that build the capacity of southern research institutions or groups would be valuable. However, several people noted that small grants will only take things so far. Institutional as well as individual researcher capacity building is needed.

Nearly 33% of respondents proposed that the Management Organisation provide capacity building training in selected areas for southern research network members, whilst 30% of respondents suggested that lead research organisations in the north could mentor and capacity build southern partners, as part of a research project. To assist this capacity building process, it was suggested that a needs assessment be undertaken to ascertain how northern institutions can best support their southern partners. This will include northern institutions stepping back into more supporting rather than lead roles. Southern institutions need to take on the role of lead partner (with regular

monitoring and support, if necessary) more often. Approximately 18% of respondents felt that written guidelines to assist southern partners at various stages of the research would be useful. Other proposals included in-country advocacy to build demand and increase understanding of why research is important. Several of respondents stated that combination strategy for capacity development of southern partners is needed.

Section 7: Strengthening the Access to Medicines Research Community

One of the anticipated outcomes of an ATM research network is that the ATM research community is strengthened. Over 50% of respondents felt that this could best be achieved through training to enable new researchers and research organisations to enter the field of access to medicines. 44% of respondents thought it would best be achieved through workshops to bring together research network institutions and groups to discuss the field, share methodologies and lessons learned would enhance the community most. A further 36% of respondents supported workshops and conferences for the dissemination of research findings to researchers, policy-makers and other interested parties as a priority. Promoting collaboration between northern and southern organisations was also a popular approach, with 39% of respondents citing this as delivering the most to enhance the ATM research community. Support for on-line sharing of recent research findings in the field scored relatively low, with only 24% of respondents citing it as the most effective approach (although support for a data repository was high – see section 4 above).

Section 8: Other

The final section of the consultation survey invited respondents to submit their outstanding suggestions or comments about the proposed ATM research network. A significant number of respondents took the opportunity to express their enthusiasm and encouragement for the initiative. Overall, it seems that the proposals have been positively received. Some of the other diverse comments received are captured in Box 4.

Box 4: Additional Comments

Development of ATM Research Network

- The ATM research network will be a useful addition to the international policy research landscape…it could become a leading platform for all research done in this area concerning developing markets
- Initiate something, which is sustainable and builds on existing structures
- Learn from existing similar initiatives
- Work in collaboration with INRUD and HAI, both of whom have a good track record in ATM research
- Make sure the research feeds into key international processes. This can be done through creating a research platform in a world capital where developing country research can be more readily channelled into international policy discussions
- The ATM research network requires sufficient human and financial resourcing. It should also include a broad network of institutions with expertise in the medicine supply chain, as well as in areas such as transparency, accountability, equity and social justice
- A small number of research centers funded by northern countries, but located in southern countries could be developed
- To start the ATM research network, a meeting for all researchers and policy makers by region in the south is required
- All effort should be made to: i) enhance the ability and desire of southern decision makers and practitioners to use “high quality” research in their decisions; ii) ensure that the majority of the ATM research network beneficiaries are researchers from the south
- DFID needs increased clarity as to the scope of the research network, as well as clear qualifications and criteria for participation

Governance of the ATM Research Network

- Given the importance of the Management Organisation, avoid nailing down every feature and function of the ATM research network. Instead, select the Management Organisation through a competitive tender and work with the selected organisation to finalise the design
- The European Observatory on Health Systems and policy would be interested to be part of the advisory committee

Focus of the ATM Research Network

- One focus of the ATM research network should be on policy impact evaluation
- The problem of access to medicines is 80% behavioural. You therefore need to have a strong social science capacity in the ATM research network
- The ATM research network needs to address issues around access to healthcare, not just access to medicines
- The ATM research network should also consider providing cost-effective training in ATM, particularly for policy-makers, medical practitioners, the pharmaceutical industry and civil society
- There needs to be a strong focus on the role of human rights in creating access to medicines

Other

- Use existing meetings or annual programmes to reduce transactional time for essential health and policy-makers
- Language is a barrier. Information, tools and ATM management mechanisms should be available in English and French as a minimum

III. NEXT STEPS IN THE DESIGN OF THE ACCESS TO MEDICINES RESEARCH NETWORK

Findings from this consultation will inform an assessment of the case, focus and recommended management options for an ATM research network.

If you would like remain informed of further developments with this initiative then please send your contact details to: atmrnconsult@dfid.gov.uk

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