



**WORLD HEALTH ORGANIZATION**

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**Meeting on Responsiveness Concepts and Measurement  
Geneva, Switzerland, 13-14 September**

**HFS/FAR/RES/00.1**

**REPORT ON WHO MEETING OF EXPERTS  
RESPONSIVENESS**

**Introduction:** This report is a summary of the major comments and findings of a meeting of experts on responsiveness and related subjects held at the WHO in Geneva, 13-14 September 2001. A list of the technical consultation participants and the agenda are shown in Annex 1. Careful planning preceded the consultation meeting. In May 2001 WHO held a small planning meeting to identify the criteria for the selection of respondents and to draw up an outline of the consultation goals.

**Objectives and Agenda:** The main objectives of the meeting were to canvass expert opinion on the concepts and measurement strategy proposed by WHO. These were described in the background reading materials, which were sent to the participants before the consultation. The main elements discussed in the background reading materials were revisited in presentations prior to the discussions. The report is structured around the key topic areas and may not follow a chronological order of the agenda. The six principal topic groupings are: conceptual issues, surveys, questionnaire, vignettes, other issues and future research.

**Main Conclusions and Recommendations:** This section summarizes the key issues. A detailed report of the meeting was sent to participants immediately after the consultations for comment and this document represents a summary of the main conclusions and recommendations.

## I. Conceptual Issues

- 1) **Defining the domains.** As this is a new area, it is clear that the domains themselves and their definitions are still evolving. Several suggestions were made. It is clear that where there is existing terminology such as that of the ethics or human rights literature, those should be applied wherever feasible. Otherwise, each concept should be formally defined and used consistently. This would be separate from the description of their characteristics for purposes of operationalization. Particularly relevant would be terminology already existing in the human rights convention for which the majority of Member States have ratified such as rights to privacy, information, participation and non-discrimination.
- 2) **Operationalising domains.** It was suggested that a matrix be developed to organise the thinking around the items in a domain. It could be possible to identify operationable items at macro, meso and micro levels. For example, in the context of Autonomy one can identify involvement in decision-making regarding what health services are offered or how they are run as an item in this domain. This would be a "macro-level" item, whereas making a decision about the type of treatment would be a more micro-level type of involvement. For policy relevance, it was felt that larger policy decisions in health systems that may affect responsiveness need also to be looked into using this approach.
- 3) **Elements within specific domains**
  - a) **Autonomy.** The scope of this domain was much debated. One suggestion was to include the concept of 'enablement' (empowerment) and self-care in autonomy. A second issue was whether involvement of the community in resource decision making should somehow be captured in this or another domain. Another issues was to include reference to information provided as well as permission sought under the notion of 'informed consent' in autonomy. Some of the discussion focused on individual autonomy versus the public good. Here, the principles of limiting versus violating rights as applied in the field of human rights was discussed.

- b) **Communication.** It was agreed to include ‘information on a healthy life style’ as part of autonomy.
- c) **Social Support Networks.** It was agreed that the present definition of social support networks needed to be expanded to include support for those under home care, community support, and support to family of patients. This expanded notion would need a new title to include the notion of “Family/community involvement” to avoid the sensitivity of using the term “support” in some cultures with the possible implication of interfering with social security activities.
- d) **Confidentiality.** The right to privacy is an important human right. The point was made that unnoticed breaches of confidentiality need to be considered. These include access to one’s own records under confidentiality. However, confidentiality is not total control over your personal information. (e.g. case of child molesters, where different social institutions are alerted of past offenders).
- e) **Prompt attention.** It was agreed that the definition of prompt attention should be expanded to include questions on how quickly people received routine care. Currently there is no distinction between the different types of care for which one could wait – and perhaps a distinction between emergency and non-emergency care could be introduced.
- f) **Dignity.** It was agreed that the term “respect” that is currently used in some questions on dignity in the survey instrument should be applied to all questions in the English version. It is a clearer term for people to understand. For translation into different languages the most appropriate term would still need to be found. Non-discrimination was seen as an integral part of being treated with dignity.
- g) **Choice.** It was agreed that the concept of choice requires further exploration. Many people felt that constraints arising from geographic access should be explored alongside financial access constraints.
- h) **Quality of basic amenities.** There was discussion about whether this should be a domain, because it might not be a priority of some governments given other more pressing concerns such as staff availability. After discussion, it was agreed that quality of basic amenities is always a component of responsiveness, regardless of the circumstances, although its weight might differ according to the setting. After measuring this domain, governments can decide what policy actions to take depending on their priorities.

- 4) Distribution of Responsiveness.** It was clear in the discussions that this was the most undeveloped area in the responsiveness work. In its measurement, WHO is trying to capture the degree of inequality existing in each country in each domain based on the calibrated responses. Suggestions were received about ways to test whether discrimination is the cause of observed inequalities in responsiveness by using population sub-groups identified in the Human Rights literature, including age and sex groups.
- 5) Universally Legitimate Expectations** There was some concern that legitimate standards need to be established. It was explained that WHO's approach to establishing the norm is to let the overall preference of the respondents establish the range of processes or behaviours expected from the health system.
- 6) Responsiveness vs. Satisfaction.** It was clarified that although the responsiveness work stems from the patient satisfaction literature, there is a clear distinction. Responsiveness measures what actually happens to people when they come in contact with the system rather than how satisfied they were or their opinions about their experiences. In some circumstances, it is conceivable that system responsiveness may actually lead to individual dissatisfaction.

## II. Measuring Responsiveness: The Survey Process

### 1) Sampling

All participants agreed on the importance of ensuring representative sampling when measuring responsiveness. A range of suggestions were made regarding the selection of respondents.

- *Capturing the experiences of children.* The use of age 18 as the cut-off point was considered to be a problem. It was pointed out that the Convention on the Rights of the Child mandates State Parties to endorse children who are capable of having opinions of their own to be allowed to speak for themselves. This suggests a cut-off age of 12 or 14.
- *Including an assessment of experience of non-users of personal health services.* The inclusion of non-users of personal health care services in the survey was considered important: in fact, 50% of respondents from the first round of surveys in the WHO Multi-country Survey Study were non-users. Suggestions on ways to do this included interviewing them on possible reasons for non-use that are related to responsiveness; and also on the non-personal health interventions that benefit them. A last resort would be a more open opinion survey of non-users, but given that many reasons for non-use are unrelated to responsiveness, this would not be a particularly good way to analyse health system responsiveness.

### 2) Implementation Issues: survey modes

- *Exit surveys.* The advantage of exit surveys is that they are cheaper than household surveys, relative to the amount of data collected. However the reporting of experience may be biased because the respondent is sensitive to the fact that they are still on the premises, and they target only users of the service. Exit surveys may be particularly useful for special marginalised groups that are under-represented in a household survey: such as people who are HIV+, those with TB, migrant workers, and hill tribes.
- *Key Informant surveys and household surveys.* Responses from these different survey modes need to be compared. This work has already begun. Key informants may be able to provide information on some parts of health system responsiveness for which households are poorer informants, e.g., the confidentiality of medical records. *Sub-national survey tools, and ensuring policy relevance.* The need to develop practical sub-national level survey tools that are relevant to both sub-national and national policy-making was raised.

### 3) Questionnaire

#### a) Content

- *Prevention, promotion and “response to emergency” care.* It was agreed that prevention and health promotion aspects need to be included in as many of the domains as feasible. It was pointed out that whilst some aspects prevention are not directly experienced by the individual and are difficult to capture in questionnaires, others such as communication of health promotion messages could be included. Questions could be asked on the kind of advice given on smoking/HIV for example, ‘Did you get information?’ ‘Was it relevant?’ and ‘Was it useful?’
- *The inpatient-outpatient distinction.* The discussion on whether this was necessary revealed a range of opinions. The discussion centred on the objectives of such disaggregation - for benchmarking or for policy formulation? It was suggested that for benchmarking it would be sufficient to consider hospital care in general, doing further disaggregation only if the findings were being used for policy analysis. However, analyses of the first round of surveys suggest that there are significant differences between in- and outpatient experiences. At the other end of the spectrum, there were suggestions about adding more inpatient questions related to the different domains, and formulating questions to relate to the different stages of hospitalisation. Because only around 10% of people surveyed in the Multi-country Survey Study population samples have had an in-patient experience in the last year, the number of observations of inpatient care was small. For that reason, a recall period of 2-5 years was suggested as being more appropriate for inpatient care than 1 year. It would increase the number of observations and people are likely to remember inpatient experiences for much longer than outpatient contacts.
- *Questions to increase analytic scope or precision.* The range of suggestions included requesting information on: whether the institution named as the ‘usual place of care’ is public or private; the main reason for the visit (including whether it is a visit related to pregnancy or a need for contraception); introducing a wider range of examples of barriers to seeking care in addition to the financial barrier..

#### b) Format and wording

- *The length and complexity of questions and their wording.* Several approaches were suggested to address this issue. The simplest would be to have the questionnaire edited by a non-health specialist, ensuring standard dictionary definitions are used, and that words open to various interpretations (such as ‘frequent’ or ‘rare’) are defined. Another suggestion was to use software that predicts the reading age of the respondents. Work to further clarify concepts, and greater precision in domain titles will also help.
- *Translation.* Attention was drawn to the need to use locally appropriate words, even where the basic language is the same.
- *Making the questionnaire easier to follow.* One suggestion was to include ‘don’t know’ and ‘no response’ categories to avoid confusion. A second was; to formulate questions in all domains using the continuum ‘never-to-always’.
- *Questionnaire length.* It was observed that long questionnaires could have difficulty obtaining ethical clearance and that the questionnaire would need to be shortened. WHO reported that one of the research strategy aims was to develop a short instrument that could be incorporated easily as a module in other surveys run by countries, if they wished.
- *Response scales:* some of the survey specialists indicated that it would be useful to review how the use of scale has affected responses.

#### c) Interpretation and analysis

Some specific comments were made on the uses of quantitative and cognitive testing to ascertain whether wording problems were affecting scores; how separate different domains are; how well respondents understand the complexly worded questions. Second, it was suggested that some analysis should be developed of how the level of health system resources affect responsiveness. A question was raised about whether individual responses of experience could be aggregated to gain a health system rating.

### III Vignettes

A wide number of useful suggestions were received about ways to improve the responsiveness vignettes.

#### 1) Vignette Formulation

The survey instrument asked respondents to rate their last contact with the health system on the different domains of responsiveness. They were offered five possible response categories – very good, good, moderate, bad and very bad. For any given level in a domain, e.g., for autonomy, people categorize their experiences in different ways, with consistent variation observed by age, sex, and country of residence, for example. This implies that their cut-points between the possible categorical responses differ. To establish how individuals use the categorical responses of “very good” to “very bad”, a series of vignettes were devised for each domain covering the entire range of the latent or unobserved variable. For each vignette, respondents were asked to rate the experience described into the different categories of response. The responses on the set of vignettes for each domain could then be analyzed to identify how cut-points on the latent scale systematically vary across individuals and across communities. This information allows a more meaningful interpretation of each individual's responses for their own encounter with the health system.

In addition to the general recommendations about simplicity, brevity and care with translation of words in the vignettes, there was much discussion about how to adapt them to local situations and cultures, and how to make them less system specific. The use of pictures and cartoons as a source of vignettes was suggested; as was having culturally equivalent substitutable phrases in some of them. It was pointed out that although local adaptation may affect cross-country comparability, it becomes necessary for even apparently simple phrases such as “across the road” to suggest distance, because roads differ in width between villages and towns. Where possible generic terms such as ‘greeted with affection’, ‘spoken to with respect’ should be used rather than describing specific gestures that are culturally sensitive, such as ‘shaking hands’. With regard to wording, using a term such as ‘your friend’ is likely to be better than a hypothetical name or referring to a relative: the former distances the issue, while the latter may be culturally sensitive.

#### 2) Content

As with the main questionnaire, several comments on missing elements and potentially misleading wording were made. For example, dignity vignettes mainly cover the issue of politeness, and they all refer to actions of nurses alone. The disease mentioned in the vignette may influence the rating given, and respondents may be more sympathetic to certain types of disease. It may therefore be important to keep the ‘illness’ constant. Some vignettes mix domains, and this should be avoided. Problems like alcoholism and homelessness within the vignette should be avoided as these have stigma attached to them.

#### 3) Other Steps to Improve Vignettes

Suggestions included:

- Providing an explanation of their purpose at the beginning of the section
- Reducing number of vignettes per domain if possible
- Using an educational expert to improve the presentation of the vignettes
- Switching the score order to have very good as five with very bad as one
- Having a visual scale shown to the respondent.

There were different views about how to address cultural sensitivity. One was to create a database of key words/key phrases to capture this (i.e. shake hands/kiss the cheek/hug) and system characteristics (hospital/health unit/clinic). Another was to avoid culturally specific references altogether.

#### 4) Testing of Vignettes

Discussions about how to validate the relationship between self-report and vignettes resulted in a number of proposals

- Structuring the questionnaire so that self-reports are followed by vignettes, then followed again by self-reports to see if the self-report scores vary. This would suggest that the vignettes are making the individual take a wider/different perspective of the domains. Another suggestion was to get individuals to paraphrase vignettes.
- Splitting vignette results by age to see if the difference that generally exists between young and old on self reports is replicated; examine whether high experience scores relate in any way to vignette scores. See whether there is a pattern in rating vignettes – are there consistently harsh and mild raters. Examine whether any respondents in a country or population respond using the categories of very good or very bad. Both extremes may be culturally unacceptable.
- Conducting standard psychometric tests on the vignettes – e.g. aiming for Kappa above 0.6; using factor analysis to see if vignettes are loading appropriately. Doing more cognitive testing of vignettes (on a larger scale than previously).
- Examining whether a rating of 1 to 5 is more desirable than the categorical variables ranging from very good to very bad.

## IV Summary of Recommendations on Future Research and Other Activities

### 1) Conceptual and analytic work

- a) Improving formal and operational definitions of domains. Further conceptualisation of the domains involving more in-depth analysis of different domains to capture issues such as cultural sensitivity. Also more work on responsiveness distribution focusing on defining different disadvantaged groups
- b) Analyses of responsiveness in the context of self-care and home care would be useful.
- c) Doing patient narratives to further study domains. These provide insight into personal experiences.
- d) Documenting the benefits to the country from the measurement of responsiveness.
- e) Involving the media and accreditation institutions for improving awareness of responsiveness.

### 2) Survey Work

- a) In terms of instrument development, the following were recommended:
  - thorough comparisons of the different modes of household surveys (face/postal, short/long versions), and between household and key informant surveys.
  - development of methods of harmonising results gained through different modes, different sampling methods, different sampling levels (national, state, provincial) etc.
  - developing in the future a survey instrument for institutional dwellers..
  - analyses of non-users to gain an understanding of their characteristics.
- b) Additional sorts of surveys were suggested for particular purposes: running parallel surveys for youth and children; testing and developing the facility survey; using key informant surveys (perhaps using a pre-selected panel of key informants) to gain views on aspects of public health that households may not experience such as whether their patient records are made available to researchers, for example; conducting panel surveys; coverage of services could be usefully addressed in a module on service provision.
- c) The need to develop the survey module in such a way that it can be annexed to existing surveys was emphasized.
- d) It was recommended that a comprehensive data collection strategy be considered, involving providers and consumers through household, exit and facility surveys.
- e) An instruction pack for countries is needed: on how to carry out surveys, training and to analyse results.

### 3) Linking to policy

There was agreement on the need to share with Member States the new data analysis methods developed for ensuring cross-population comparability of results. Issues and suggestions about ways to increase the government's role in measuring and improving responsiveness, and ways of communicating findings to policy makers, providers and consumers included:

- The value of involving providers in the entire discussion of responsiveness, not only the measurement step through surveys. This will raise awareness and commitment to new concepts and practices.
- Developing appropriate 'reporting systems' to share findings with facilities and consumers.
- Undertaking analytical work on the sorts of incentives that lead to improved responsiveness. This would include looking at regulatory frameworks to investigate whether the existence of patients' rights and charters improves responsiveness as well as studying the effect of legislation related to responsiveness issues.

**ANNEX**

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**AGENDA**

13-14 September 2001, WHO Geneva

**DAY 1**

**Theme A: Responsiveness Concepts**

1. Welcome: 8:30-8:40 *Christopher Murray*
2. Objectives of the Meeting: 8:40-8:55 *Kei Kawabata*
3. Responsiveness Concepts and Discussion : 8:55-9:55 *Amala de Silva*  
*Discussion: what is our understanding of responsiveness concepts, problems with them, overlaps and missing dimensions?* *Chair: Pedro Ferreira*
4. Responsiveness Roots in Ethics: 9:55-10:20 *Reidar Lie*
5. Responsiveness Roots in Human Rights: 10:20-10:30 *Helena Nygren-Krug*
6. Summary of Main Conceptual Issues: 10:30 – 10:40

Tea: 10:40-11:00

**Theme B: Operationalising Responsiveness**

7. Results of WHO Responsiveness Surveys: 11:00-12:30 *Nicole Valentine*  
*Discussion: what are the main implications of results and remaining challenges for improving the methods* *Chair: Leo Morales*

LUNCH (12:30-13:45)

8. Responsiveness Items: 13:45-14:15 *Charles Darby*
9. Group work A:  
*What items best exemplify the responsiveness domains and are most cross-culturally applicable? What new items should be added? (4 groups to appoint rapporteur to report back in plenary): 14:15-15:30*

Tea: 15:30-16:00

10. Discussion and Summary of Findings in Plenary: 16:00- 17:00 *Chair: Sammy Gadalla*
11. Reception in cafeteria: 18:00-19:00

**DAY 2**

**Theme C: Use of Vignettes**

12. Vignettes, their Effectiveness and Proposed Strategies for Improvement: 8:45-9:15  
*Nicole Valentine*

13. *Group work B:*  
*Go through sample of vignettes and self report questions.*  
*What works, why and what doesn't and why?*  
*(4 groups to appoint rapporteur to report back in plenary): 9:15-10:30*

Tea: 10:30-10:50

14. Discussion and Summary of Findings in Plenary: 10:50- 11:15 *Chair: Luis Justo*

**Theme D: Framing and Sampling**

15. Introductory Questions: different options and challenges: 11:15-11:45  
*Angela Coulter*

16. *Group work C:*  
*What is the best way to introduce the questionnaire to the respondent in a household survey and what sampling biases do we need to be aware of in different settings (e.g. minorities, institutionalised, non-users): 11:45-13:00*

LUNCH: 13:00-14:00

17. Presentation and Discussion of Findings in Plenary: 14:00-14:45 *Chair: Bedirhan Ustun*

**Theme E: Use of Data and Further Research**

18. Discussion of Ways of Making Responsiveness Information Useful in Countries: 14:45-15:30  
*Viroj Tangcharoensathien*

Tea:15:30-16:00

19. Discussion of Future Research Agenda Priorities: 16:00-16:45 *Chair: Abdelhay Mechbal*

20. Summary and closure of meeting: 16:45-17:00  
*Christopher Murray*

**Group Facilitators and Note-Takers :**

Group 1: Amala De Silva and Helena Nygren-Krug

Group 2: Charles Darby and Hedwig Goede

Group 3: Angela Coulter and Kei Kawabata

Group 4: Sammy Gadalla, Juan Pablo Ortiz and Jane Cottingham

Overall Conference Note-Taker : Amala de Silva

**Materials for Participants:**

Note on Description of Main Issues and Challenges with Annex Listing Revised Definitions

De Silva A, Murray CJL. 2000. *A framework for measuring responsiveness*. Geneva: WHO (GPE Discussion Paper No. 32) (original conceptual paper)

Darby C, Valentine N, De Silva A, Murray CJL. 2000. *World Health Organization (WHO): strategy on measuring responsiveness*. Geneva: WHO (GPE Discussion Paper No. 23).