



# Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention

## **Community Education in Health Aspects of Genetics: A Capacity Building Project**

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**Introduction:**

- In Egypt Rural community is bigger than Urban; it represents 57.4% and is growing faster. From the 78 million Egyptians; 45.17 million live in rural areas. There are about 5633 rural villages in the country and they almost have similar infrastructure of governmental services and facilities like health and education.
- Rural development in Egypt has a long history traced back to the 19<sup>th</sup> century, and recently it has been sought to incorporate the notion of sustainable development. Rural community health education is one aspect of rural development.
- Accordingly, we designed a 2 years capacity building model approach addressing the needs for rural community education in some health aspects of genetics.

**Goal:**

To provide genetic health education to rural community that should be suitable to their needs. This was achieved through the following:

1. Study the current situation of rural community.
2. Identify needs.
3. Design appropriate health education messages.
4. Educate and train community outreach visitors to provide continuous health education to the selected community.

**Preparation phase:**

- ❖ Selection of the setting
- ❖ Selection of the target population
- ❖ Selection of health providers
- ❖ Gathering information on the selected community concerning level of education, occupation, resources, Family size and family planning, M/F ratio, Consanguinity, Culture (beliefs, behaviours, attitude, religion)
- ❖ Collecting information on the selected settings concerning educational facilities, health facilities, geographic map and boundaries, urban/rural land.

**Setting:**

The selected setting was Om-Khenan village, it is 4 km<sup>2</sup> in diameter, and is located in Giza governorate in the North of Upper-Egypt in a city called El-Hawamdeya. It is a rural village having similar socio-economic and population characteristics. The infrastructure for governmental services including health and education facilities and services are like those in the majority of the rural villages in Egypt, so it could be considered as a model for other villages and the same health education approach that was applied in the demonstration project could be also applied in many other villages thus serving a large number of the population.

**Criteria for selection of the setting:**

1. Rural village.
2. Available health facilities.
3. Accessibility of genetic services.
4. Accessible for the team.

**Criteria for selection of the target population:**

1. All age groups are represented.
2. Unprivileged community.

3. High prevalence of illiteracy.
4. High consanguinity rate.
5. No previous health education in the field of genetics.

**Criteria for selection of health education providers:**

Trained community outreach visitors (COV) were selected to provide health education to the community. Six COV were selected to do the training; they are University graduates and received a package of training courses in the field of communication, family planning, reproductive health, antenatal care, postnatal care, prevention of infectious and communicable diseases, child healthcare and vaccination and other specialized courses. They are officially employees in the ministry of health.

The COV were chosen because they live in the same community; they are respected and trusted by the community. They are officially allowed to do home visits for family planning and health education for the promotion of primary health care services mainly for the maternal and child health care services.

**Demography and target population:**

| Age Group    | 1996        |              |             |              |              |              | 2006         |             |             |             |              |              |
|--------------|-------------|--------------|-------------|--------------|--------------|--------------|--------------|-------------|-------------|-------------|--------------|--------------|
|              | M           |              | F           |              | Total        |              | M            |             | F           |             | Total        |              |
|              | No.         | %            | No.         | %            | No.          | %            | No.          | %           | No.         | %           | No.          | %            |
| 0 - 5        | 2010        | 49.97        | 2012        | 50.03        | 4022         | 100.0        | 2590         | 50.3        | 2562        | 49.7        | 5152         | 100.0        |
| >5 - 20      | 2437        | 52.97        | 2163        | 47.03        | 4600         | 100.0        | 3156         | 53.0        | 2776        | 46.9        | 5952         | 100.0        |
| >20 - 40     | 2428        | 50.65        | 2366        | 49.35        | 4794         | 100.0        | 3181         | 51.1        | 3044        | 48.9        | 6223         | 100.0        |
| >40 - 60     | 1338        | 54.50        | 1117        | 45.50        | 2455         | 100.0        | 1716         | 54.7        | 1418        | 45.3        | 3134         | 100.0        |
| > 60 -       | 434         | 49.94        | 435         | 50.06        | 869          | 100.0        | 533          | 50.1        | 531         | 49.9        | 1064         | 100.0        |
| <b>Total</b> | <b>8647</b> | <b>51.65</b> | <b>8093</b> | <b>48.35</b> | <b>16740</b> | <b>100.0</b> | <b>11176</b> | <b>51.9</b> | <b>1035</b> | <b>48.1</b> | <b>21525</b> | <b>100.0</b> |

In 2008 the total population of Om-Khenan village was 22,755. The number of live births was 705.

Five hundred families were selected. The technique of sampling was systematic random sampling to insure good representation of the village population.

**Occupation:**

- ❖ Manual workers: 45%
- ❖ Farmers: 40%
- ❖ Street dwellers: 8%
- ❖ No occupation: 7%
- ❖ Females:
  - House wives: 68%
  - Farmers: 10%
  - Manual workers: 22%

**Educational and health facilities:  
Number of schools in the village**

| Type of School | Public | Private |
|----------------|--------|---------|
| 1) Primary     | 2      | 1       |
| 2) Preparatory | 1      | 1       |
| 3) Secondary   | 1      | -       |
| 4) Azhar       | -      | -       |

**Health facilities:**

- Rural health care unit
- Private clinics
- Easy access to:
  1. the general hospital of El-Hawamdeya city
  2. Medical center that belongs to the sugar company in El-Hawamdeya
  3. Genetic counseling clinic in Giza governorate

**Important rates:**

- ❖ Births: 23.6/1000 population
- ❖ Deaths: 4.1/1000 population
- ❖ Marriages: 25/month
- ❖ Consanguinity rate: 32%
- ❖ Illiteracy rate: 42%
- ❖ Home delivery: 19%
- ❖ Vaccination coverage: 98.9%
- ❖ Screening coverage: 99.7%
- ❖ Use of contraception: 32.4%

**Population culture:**

- ❖ Religion:
  - 85% Muslims
  - 15% Christian
- ❖ Beliefs:
  - God and fate
  - Family is sacred
  - Abortion is a sin
- ❖ Concept:
  - Provide what's necessary for their children education and marriage

**Implementation phase:**

- ❖ Community:
  - Situation Analysis Survey
  - Needs Assessment Survey
  - Health Messages
- ❖ Physicians:
  - Needs Assessment Questionnaire
  - Focus Group Discussion
  - Seminars

- ❖ COV:
  - Training for surveys implementation
  - Manual for Training

**Current situation analysis survey:**

- Questionnaire preparation
- Training community outreach visitors (COVs) on the utilization of the questionnaire and how to interview the selected families
- Pilot testing on the application of questionnaire and readjusting the questionnaire according to the comments of COVs and results of the pilot.
- Fieldwork: home visits for the application of the questionnaire (531 families)
- Data collection
- Revision of sheets collected after filling the questionnaire
- Double data entry, cleaning and validation
- Data analysis

**Goal:**

To find out the current health status of the selected families and to recognize the most common genetic problems in order to plan for health education and design health messages suitable for them.

- ❖ Target Group
  - Families from OM Khenan village (n = 531).
  - Sampling: Systemic random sampling.
- ❖ Implementers: Community outreach Visitor
- ❖ Settings: Homes of the selected families
- ❖ Pilot testing of the questionnaire
- ❖ Duration of the field work: 1 month
- ❖ COV interviewed 100 families, 4 families/day
- ❖ Supervision and quality check by the central team

## Results:

### Basic data

| Data                                      |                                  | No  | %    |
|---|----------------------------------|-----|------|
| Source of questionnaire Information       | Wife                             | 415 | 80%  |
|   | Others                           | 107 | 20%  |
| Religions of contributing families        | Muslim                           | 398 | 85%  |
|   | Christian                        | 89  | 15%  |
| Degree of Parents Consanguinity           | None                             | 335 | 65%  |
|   | Close                            | 101 | 19%  |
|   | Less than 2 <sup>nd</sup> degree | 83  | 16%  |
| No of current off-springs per each family | 0                                | 32  | 6    |
|   | 1                                | 69  | 13   |
|   | 2                                | 89  | 16.8 |
|   | 3                                | 94  | 17.7 |
|   | 4                                | 99  | 18.7 |
|   | 5                                | 63  | 11.8 |
|   | >5                               | 82  | 15.4 |
|   | >10                              | 3   | 0.6  |
| No of dead off-springs per each family    | 0                                | 378 | 71.2 |
|   | 1                                | 85  | 16   |
|   | 2                                | 39  | 7.3  |
|   | 3                                | 19  | 3.6  |
|   | >3                               | 10  | 1.9  |

### Maternal data:

|   |      |     |      |
|---|------|-----|------|
| No of pregnancy occurred per each mother  | 0    | 15  | 2.9  |
|   | 1    | 59  | 11.3 |
|   | 2    | 69  | 13.2 |
|   | 3    | 76  | 14.6 |
|   | 4    | 85  | 16.3 |
|   | 5    | 45  | 8.6  |
|   | >5   | 154 | 29.6 |
|   | >10  | 18  | 3.5  |
| No of abortion occurred to each mother    | 0    | 362 | 68.6 |
|   | 1    | 99  | 18.7 |
|   | 2    | 37  | 7    |
|   | 3    | 14  | 2.7  |
|   | 4    | 9   | 1.7  |
|   | 5    | 2   | 0.4  |
|   | >5   | 5   | 0.9  |
| No of deliveries occurred per each mother | 0    | 35  | 6.7  |
|   | 1    | 65  | 12.2 |
|   | 2    | 84  | 15.8 |
|   | 3    | 83  | 15.6 |
|   | 4    | 82  | 15.4 |
|   | 5    | 51  | 9.6  |
|   | >5   | 124 | 23.4 |
| >10                                       | 7    | 1.3 |      |
| Incidental pre-mature deliveries          | None | 520 | 98   |
|   | Yes  | 11  | 2    |

Data of Common Genetic related Disorders among target families and their relatives:

| 531 Families                                  | Family Members |         |          |      | Relative Members |      |          |      |
|---|----------------|---------|----------|------|------------------|------|----------|------|
|   | Alive No       | Dead No | Total No | %    | Alive            | Dead | Total No | %    |
| <b>Congenital anomalies</b>                   | 36             | 3       | 39       | 7.3  | 86               | 13   | 99       | 18.6 |
| <b>Motor Disabilities</b>                     | 30             | 2       | 32       | 6    | 92               | 13   | 105      | 19.7 |
| <b>Hearing Disabilities</b>                   | 21             | 2       | 23       | 4.3  | 46               | 1    | 47       | 8.8  |
| <b>Speech Disabilities</b>                    | 31             | -       | 31       | 5.8  | 75               | 1    | 76       | 14.3 |
| <b>Vision Disabilities</b>                    | 64             | 2       | 66       | 12.4 | 78               | 7    | 85       | 16   |
| <b>Mental Disabilities</b>                    | 41             | 3       | 44       | 8.3  | 73               | 8    | 81       | 15.2 |
| <b>Down Syndrome</b>                          | 1              | 1       | 2        | 0.4  | 22               | 1    | 23       | 4.3  |
| <b>Congenital heart Disease</b>               | 24             | 4       | 28       | 5.2  | 28               | 16   | 44       | 8.2  |
| <b>Congenital anemia</b>                      | 5              | -       | 5        | 0.9  | 20               | 4    | 24       | 4.5  |
| <b>Diabetes (type II)</b>                     | -              | 14      | 14       | 2.6  | 291              | 53   | 344      | 65   |
| <b>Bronchial Asthma</b>                       | 53             | 6       | 59       | 11   | 74               | 35   | 109      | 20.5 |
| <b>Hypertension-Coronary vascular disease</b> | 116            | 9       | 225      | 42   | 305              | 125  | 430      | 81   |

**Community Knowledge, attitude and practice (KAP) assessment survey:**

- ❖ Importance:
  - 1) Determining community needs as regards information on genetic diseases, prevention and availability of genetic services.
  - 2) The choice of health education messages.
  - 3) The ways of presenting such messages.
  - 4) The choice of the most suitable target group for health education.
  - 5) Outcome evaluation.
- ❖ Target group: women of selected families
- ❖ Implementers: COV
- ❖ Main points in the questionnaire:
  - 1) Women's knowledge concerning genetic diseases.
  - 2) Women's attitude as regards preventive approaches for genetic disorders.
  - 3) Women's practice during pregnancy for the prevention of genetic and congenital disorders.
  - 4) Information needs concerning genetic diseases.
  - 5) Women's needs for the prevention of genetic and congenital disorders.
  - 6) Women's needs for improving public health services.

**Questionnaire for community needs assessment: KAP in relation to genetic conditions**

(1) Socio-demographic characteristics:

|   |                           |  |
|---|---------------------------|--|
| 1 | Age                       | ( )  |
| 2 | Are you currently married | Married <input type="checkbox"/> Not married <input type="checkbox"/>  |
| 3 | Do you have any children  | Yes I have children <input type="checkbox"/> No I don't <input type="checkbox"/>   |
| 4 | Are you currently married | Yes <input type="checkbox"/> No <input type="checkbox"/>   |
| 5 | Can you read and write    | Illiterate <input type="checkbox"/> Read/write <input type="checkbox"/><br>Basic/intermediate <input type="checkbox"/> High <input type="checkbox"/> |

(2) Women's' Knowledge about congenital and genetic diseases:

|    |   |   |
|----|---|---|
| 1  | Do you know some information about genetic and congenital diseases in children and from where did you get those information | Yes <input type="checkbox"/> No <input type="checkbox"/><br>Source/s of information:  |
| 2  | Do you know what is genetic counseling  | Yes <input type="checkbox"/> No <input type="checkbox"/><br>If yes, do you know where can you receive such service -----  |
| 3  | Did you know that genetic disorders or congenital anomalies can cause motor, learning and cognitive disabilities            | Yes <input type="checkbox"/> No <input type="checkbox"/>  |
| 4  | Do you think that consanguineous marriage can cause genetic diseases in the offspring                                       | Yes <input type="checkbox"/> No <input type="checkbox"/>  |
| 5  | Do you think that German measles vaccination is useful and why  | Yes <input type="checkbox"/> No <input type="checkbox"/><br>If yes:<br>for protection from congenital disorders <input type="checkbox"/> for other reasons <input type="checkbox"/> |
| 6  | Did you take any vitamins before or during pregnancy and why  | Yes <input type="checkbox"/> No <input type="checkbox"/><br>If yes:<br>for protection from congenital disorders <input type="checkbox"/> for other reasons <input type="checkbox"/> |
| 7  | Did you follow a special diet during pregnancy and why  | Yes <input type="checkbox"/> No <input type="checkbox"/><br>If yes:<br>for protection from congenital disorders <input type="checkbox"/> for other reasons <input type="checkbox"/> |
|    | Did you avoid any source of infection during pregnancy and why  | Yes <input type="checkbox"/> No <input type="checkbox"/><br>If yes:<br>for protection from congenital disorders <input type="checkbox"/> for other reasons <input type="checkbox"/> |
| 9  | Did you follow proper spacing between pregnancies and why   | Yes <input type="checkbox"/> No <input type="checkbox"/><br>Reasons:  |
| 10 | Do you visit family planning clinics  | No <input type="checkbox"/> Yes <input type="checkbox"/><br>Sometimes <input type="checkbox"/> Regularly <input type="checkbox"/>   |



(3) Women's attitude in relation to specific situations:

|    |   |  |
|----|---|--|
| 1  | Would you advise your daughter to have premarital examination and counseling  | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |
| 2  | Would you advise your daughter to marry from the family   | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |
| 3  | Would you advise your daughter to space pregnancies   | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |
| 4  | What is the appropriate pregnancy spacing period (years)  | ( )Year  |
| 5  | What is the appropriate number of offspring   | ( )  |
| 6  | Do you think that contraception is against religion   | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |
| 7  | Do you think that abortion is against religion  | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |
| 8  | What advice would you give if your friend discovered that she is pregnant with a baby who have a serious genetic or congenital disorder | Consult doctor <input type="checkbox"/><br>Follow the opinion of her husband <input type="checkbox"/><br>Do an abortion <input type="checkbox"/><br>Consult the sheikh or priest before deciding for abortion <input type="checkbox"/> |
| 9  | What advice would you give to your friend if she had a child with a serious inherited disorder  | Consult a doctor <input type="checkbox"/><br>Get pregnant and do antenatal testing <input type="checkbox"/><br>Get pregnant & hope to have a normal baby <input type="checkbox"/><br>Never get pregnant <input type="checkbox"/>       |
| 10 | Do you agree on the belief that says that mentally retarded children including Down syndrome are considered a blessing (Good Omen)      | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |
| 11 | Do you agree on the belief that the newborn must be confined to home till he/she is 40 days old   | Yes <input type="checkbox"/><br>No <input type="checkbox"/>  |

(4) Women's information needs related to genetic diseases:

|   |   |  |
|---|---|--|
| 1 | Would you like to know more information about congenital genetic diseases | Yes <input type="checkbox"/> No <input type="checkbox"/>   |
| 2 | What is the proper age for getting such information                       | School age <input type="checkbox"/><br>Immediately before marriage <input type="checkbox"/><br>Immediately after marriage <input type="checkbox"/><br>Any age <input type="checkbox"/>   |
| 3 | What is the preferred way of getting such information                     | TV <input type="checkbox"/> Newspapers <input type="checkbox"/><br>Radio Seminars <input type="checkbox"/><br>home education through health visitors <input type="checkbox"/><br>Health education brochures, leaflets <input type="checkbox"/> Other ways <input type="checkbox"/> |

|   |  |   |
|---|--|---|
| 4 | Who would you prefer to get genetic health information from  | Specialized male physician <input type="checkbox"/><br>Specialized female physician <input type="checkbox"/><br>Trained nurse/health visitor <input type="checkbox"/>                   |
| 5 | Preferred location to receive genetic health education       | Home <input type="checkbox"/> Healthcare setting <input type="checkbox"/><br>Mosques/churches <input type="checkbox"/><br>Clubs <input type="checkbox"/> NGO's <input type="checkbox"/> |
| 6 | Would you like your husband to be aware of genetic diseases  | Yes <input type="checkbox"/> No <input type="checkbox"/>  |
| 7 | Would you like your children to be aware of genetic diseases | Yes <input type="checkbox"/> No <input type="checkbox"/>  |

(5) Women's needs for improving public health services:

|   |   |  |
|---|---|--|
| 1 | Reproductive health services            | Improve quality of services <input type="checkbox"/><br>Start early for schoolgirls <input type="checkbox"/><br>Good selection of trained physicians to provide the services <input type="checkbox"/><br>Good communication skills of service providers <input type="checkbox"/><br>None <input type="checkbox"/>  |
| 2 | Antenatal care services                 | Improve quality of services <input type="checkbox"/><br>More health education about genetic diseases <input type="checkbox"/><br>Provide Facilities for antenatal testing and screening <input type="checkbox"/> Good selection of trained physicians to provide the services <input type="checkbox"/><br>Good communication skills of service providers <input type="checkbox"/><br>None <input type="checkbox"/>   |
| 3 | Genetic counseling services             | Improve quality of services <input type="checkbox"/><br>More health education about genetic diseases <input type="checkbox"/><br>Start early for schoolgirls <input type="checkbox"/><br>Good selection of trained physicians to provide the services <input type="checkbox"/><br>Good communication skills of service providers <input type="checkbox"/><br>None <input type="checkbox"/>   |
| 4 | Prevention and care of genetic diseases | Improve quality of services <input type="checkbox"/><br>Increase number and types of genetic services <input type="checkbox"/><br>More health education about genetic diseases <input type="checkbox"/><br>Start early for schoolgirls <input type="checkbox"/><br>Good selection of trained physicians to provide the services <input type="checkbox"/><br>Good communication skills of service providers <input type="checkbox"/><br>None <input type="checkbox"/> |

(6) Women's needs for prevention of genetic and congenital disorders:

|   |   |  |
|---|---|--|
| 1 | For you to start taking preventive measures for genetic and congenital disorders in your family what do you think is needed | Accessibility to genetic services <input type="checkbox"/><br>Increase types and quality of services <input type="checkbox"/><br>Making premarital testing mandatory by law <input type="checkbox"/><br>Raising awareness about possible ways of prevention of genetic |
|---|---|--|

|  |  |  |
|--|--|--|
|  |  | disorders <input type="checkbox"/><br>Forbidding consanguineous marriages <input type="checkbox"/> |
|--|--|--|

(7) Influence on women's opinion (preferred advisor):

|   |   |   |
|---|---|---|
| 1 | Who is the person that you listen to his/her advice | <u>From inside the family:</u><br>Husband <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/><br>Grand-parents <input type="checkbox"/> Mother in law <input type="checkbox"/><br>Other family members <input type="checkbox"/> None <input type="checkbox"/><br><u>From outside the family:</u><br>Sheikh or priest <input type="checkbox"/><br>Friends <input type="checkbox"/><br>Mayor of the village <input type="checkbox"/> others <input type="checkbox"/> |
| 2 | Who is the decision maker in your family            | I am <input type="checkbox"/> My husband <input type="checkbox"/> Both of us <input type="checkbox"/><br>Mother in law <input type="checkbox"/> other.....  |

Comments of community outreach visitor:

|                |
|----------------|
| .....<br>..... |
|----------------|

### Highlight on results of the survey:

- ❖ 87.2% needed information on genetic diseases.
- ❖ 69.1% preferred to receive information immediately before marriage while 29.5% selected school age as the best age for genetic health education.
- ❖ Needs for genetic services:
  - Needs for accessible and affordable genetic services 86.2%.
  - Making premarital examination and genetic counseling mandatory by law 47.1%.
  - Forbidding consanguineous marriage 7.6%.
- ❖ Preferred advisor: husband 61.5%.
- ❖ Decision maker in the family: both husband and wife 72%.
- ❖ Significant relation between knowledge and:
  - Age
  - Marital status
  - Level of education
- ❖ Significant relation between practice and:
  - Age
  - Marital status
  - Level of education
  - Presence of children

### Relation between women's knowledge, attitude and practice:

|                       | Knowledge                       |      |                                |      | X2 Test | p-value    |
|-----------------------|---------------------------------|------|--------------------------------|------|---------|------------|
|                       | Satisfactory (score $\geq$ 50%) |      | Unsatisfactory (score $<$ 50%) |      |         |            |
|                       | No.                             | %    | No.                            | %    |         |            |
| Total attitude:       |                                 |      |                                |      |         |            |
| Positive (60%+)       | 348                             | 78.7 | 94                             | 21.3 | 27.19   | $<$ 0.001* |
| Negative ( $<$ 60%)   | 28                              | 47.5 | 31                             | 52.5 |         |            |
| Total practice:       |                                 |      |                                |      |         |            |
| Adequate (60%+)       | 184                             | 86.0 | 30                             | 14.0 | 22.62   | $<$ 0.001* |
| Inadequate ( $<$ 60%) | 188                             | 67.4 | 91                             | 32.6 |         |            |

### Relation between women's attitude and practice:

|                       | Attitude                    |      |                          |      | X2 Test | p-value |
|-----------------------|-----------------------------|------|--------------------------|------|---------|---------|
|                       | Positive (score $\geq$ 60%) |      | Negative (score $<$ 60%) |      |         |         |
|                       | No.                         | %    | No.                      | %    |         |         |
| Total practice:       |                             |      |                          |      |         |         |
| Adequate (60%+)       | 196                         | 91.6 | 18                       | 8.4  | 4.54    | 0.03*   |
| Inadequate ( $<$ 60%) | 238                         | 85.3 | 41                       | 14.7 |         |         |

(\*) Statistically significant at  $p < 0.05$

### Physicians' needs assessment survey:

#### Objectives:

1. To determine the physicians' situation as regards their study, training and knowledge in genetics.
2. To recognize their needs concerning genetic knowledge and practice.
3. To verify their satisfaction with the current genetic services in Egypt.
4. To identify current obstacles for the provision of genetic services.

Study Group:

- ❖ 50 physicians from Om Khenan village and El-Hawamdya health facilities:
  - 25 general practitioners
  - 22 specialists (Paediatricians, OBGY, family physicians)
  - 3 consultants

## Results:

|     | Current situation: Knowledge and practice   |   | No | %  |
|-----|---|---|----|----|
| 1A  | Job description   | 1- Consultants <input type="checkbox"/>                 | 3  | 6  |
|     |   | 2- GP <input type="checkbox"/>                          | 25 | 50 |
|     |   | 3 – Specialist <input type="checkbox"/>                 | 22 | 44 |
| 3A  | Experience since graduation   | 1- < 5 years <input type="checkbox"/>                   | 20 | 40 |
|     |   | 2- 5-10 years <input type="checkbox"/>                  | 27 | 54 |
|     |   | 3- > 10 years <input type="checkbox"/>                  | 3  | 6  |
| 4A  | Duration of work in current position  | 1- < 5 years <input type="checkbox"/>                   | 20 | 40 |
|     |   | 2- 5-10 years <input type="checkbox"/>                  | 27 | 54 |
|     |   | 3- > 10 years <input type="checkbox"/>                  | 3  | 6  |
| 5A  | Did you study human genetics?   | 1-No  | 5  | 10 |
|     |   | 2-During University study <input type="checkbox"/>      | 19 | 38 |
|     |   | 3-Post graduate education <input type="checkbox"/>      | 23 | 46 |
|     |   | 4-Training courses in genetics <input type="checkbox"/> | 3  | 6  |
|     |   | Others  |    |    |
| 6A  | While patient assessment; when do you consider genetic background?  | 1-Never, I am dealing with his acute problems           | 5  | 10 |
|     |   | 2-If the complain is related to inherited disorder      | 42 | 84 |
|     |   | 3-As a routine step of the examination                  | 3  | 6  |
| 7A  | Can you mention 3 of genetic disorders you usually see during practice:   | correct answer <input type="checkbox"/>                 | 42 | 84 |
|     |   | wrong answer <input type="checkbox"/>                   | 8  | 16 |
| 8A  | How often have you been consulted in genetic related diseases?  | 1. Never <input type="checkbox"/>                       | 35 | 70 |
|     |   | 2. Few <input type="checkbox"/>                         | 10 | 20 |
|     |   | 3. Some Times <input type="checkbox"/>                  | 3  | 6  |
|     |   | 4. frequent <input type="checkbox"/>                    | 2  | 4  |
| 9A  | How often do you give an advice for a premarital situation?   | 1- Never <input type="checkbox"/>                       | 35 | 70 |
|     |   | 2- Few <input type="checkbox"/>                         | 12 | 24 |
|     |   | 3- Some Times <input type="checkbox"/>                  | 3  | 6  |
|     |   | 4- frequent <input type="checkbox"/>                    | -  | -  |
| 10A | Are you aware about the facilities where genetic services are provided in Egypt?<br>If Yes, mention where you are referring suspected patients? | 1-No <input type="checkbox"/>                           | -  | -  |
|     |   | 2-I am not sure <input type="checkbox"/>                | 25 | 50 |
|     |   | 3-Yes: to Ministry of health at:                        | 15 | 30 |
|     |   | 4-Yes: to Universities at:<br>National Research Center  | 10 | 20 |
|     |   | Yes: to:  | -  | -  |
| 11A | How often do you refer patients for genetic counseling?   | 1- Never <input type="checkbox"/>                       | 28 | 56 |
|     |   | 2- Some Times <input type="checkbox"/>                  | 17 | 34 |
|     |   | 3- frequent <input type="checkbox"/>                    | 5  | 10 |

|                        |   |   |    |    |
|------------------------|---|---|----|----|
| 12A                    | What are the obstacles facing the genetic services provision in Egypt?<br>(You can choose more than one item) | Poor community awareness                                | 43 | 86 |
|                        |   | Customs & beliefs                                       | 45 | 90 |
|                        |   | Fear of Stigmatization                                  | 10 | 20 |
|                        |   | Community refusal                                       | 4  | 8  |
|                        |   | Shortage of specialist                                  | 30 | 60 |
|                        |   | Deficient training of health providers                  | 34 | 68 |
|                        |   | Absence of system                                       | 47 | 94 |
|                        |   | Health political issues                                 | 47 | 94 |
|                        |   | Is not considered a priority compared to other problems | 45 | 90 |
|                        |   | Legalization & religious issues                         | 25 | 50 |
|                        |   | Limited resources                                       | 40 | 80 |
| Others: Please Mention |   |   |    |    |

| Physician satisfaction |   |   |    |    |
|------------------------|---|---|----|----|
| 1B                     | Are you satisfied with current physician's training in genetics                                     | 1-Highly satisfied <input type="checkbox"/> | -  | -  |
|                        |   | 2-Satisfied <input type="checkbox"/>        | -  | -  |
|                        |   | 3-Neutral <input type="checkbox"/>          | 3  | 6  |
|                        |   | 4-Unsatisfied <input type="checkbox"/>      | 47 | 94 |
|                        |   |   |    |    |
| 2B                     | Are you satisfied with current community awareness on prevention and treatment of genetic disorders | 1-Highly satisfied <input type="checkbox"/> | -  | -  |
|                        |   | 2-Satisfied <input type="checkbox"/>        | 3  | 6  |
|                        |   | 3-Neutral <input type="checkbox"/>          | 10 | 20 |
|                        |   | 4-Unsatisfied <input type="checkbox"/>      | 37 | 74 |
| 3B                     | Are you satisfied with current genetic services provided in Egypt                                   | 1-Highly satisfied <input type="checkbox"/> | 5  | 10 |
|                        |   | 2-Satisfied <input type="checkbox"/>        | 10 | 20 |
|                        |   | 3-Neutral <input type="checkbox"/>          | 5  | 10 |
|                        |   | 4-Unsatisfied <input type="checkbox"/>      | 30 | 60 |

| Do you agree on the following issues: |  |                                     |    |     |
|---------------------------------------|--|-------------------------------------|----|-----|
| 1C                                    | Egyptian community currently can accept and is in need for genetic counseling services?  | 1-Agree <input type="checkbox"/>    | 46 | 92  |
|                                       |  | 2-Neutral <input type="checkbox"/>  | 2  | 4   |
|                                       |  | 3-Disagree <input type="checkbox"/> | 2  | 4   |
| 2C                                    | Teaching human genetics in schools is an effective means for raising community awareness                                       | 1-Agree <input type="checkbox"/>    | 48 | 96  |
|                                       |  | 2-Neutral <input type="checkbox"/>  | 2  | 4   |
|                                       |  | 3-Disagree <input type="checkbox"/> | -  | -   |
| 3C                                    | Community genetic services should be provided through 1ry health care facilities.  | 1-Agree <input type="checkbox"/>    | 50 | 100 |
|                                       |  | 2-Neutral <input type="checkbox"/>  | -  | -   |
|                                       |  | 3-Disagree <input type="checkbox"/> | -  | -   |
| 4C                                    | Simple and practical health messages directed to community could be an effective method for the prevention of genetic diseases | 1-Agree <input type="checkbox"/>    | 50 | 100 |
|                                       |  | 2-Neutral <input type="checkbox"/>  | -  | -   |
|                                       |  | 3-Disagree <input type="checkbox"/> | -  | -   |
| 5C                                    | Manual for genetic disorders (Book   | 1-Agree <input type="checkbox"/>    | 44 | 88  |

|    |   |   |               |               |
|----|---|---|---------------|---------------|
|    | or CD) is a priority for physicians practice                                      | 2-Neutral <input type="checkbox"/><br>3-Disagree <input type="checkbox"/>                                     | 2<br>4        | 4<br>8        |
| 6C | Online education could be an effective method for continuous training in genetics | 1-Agree <input type="checkbox"/><br>2-Neutral <input type="checkbox"/><br>3-Disagree <input type="checkbox"/> | 25<br>3<br>22 | 50<br>6<br>44 |

### Focus group discussion for physicians:

- ❖ Objectives:
  - To determine physicians' needs for information concerning clinical genetics, genetic services provided in Egypt and possible ways of referral.
  - To identify the best possible way for community education and suggested education materials.
- ❖ Target Groups:
  - Ten primary care physicians from Om Khenan PHC unit.
  - Twenty four secondary and tertiary care physicians from Al Hawamdya Hospital, Sugar company medical centre and private medical centres.
- ❖ Open ended questions addressing the following points:
  - The minimum information in clinical genetics required by the physicians to be able to recognize genetic disorders and refer patients to the genetic centres.
  - Available information on genetic services provided in Egypt.
  - Needs for education and possible approaches.
  - Materials needed for genetic health education.
  - Best targets for genetic health education.
- ❖ Results:
  - The majority of the physicians acknowledged the need for training courses, seminars and workshops in the field of genetics.
  - Some physicians did not have any information on genetic services provided in Egypt.
  - Some physicians needed the address for premarital diagnosis and counseling services together with the list of investigations needed and a price list.
  - They asked for an official referral card to the genetic counseling clinics to be available in their working place.
  - All the physicians asked for a simplified book with photos on how to recognize the most common genetic disorders in Egypt and possible ways of prevention and management.
  - They confirmed that the COV is the best candidate for community health education.
  - Some physicians recommended the use of TV spots and newspaper ads for transferring knowledge to the community.
  - Some others suggested social mobilization campaigns with interactive approach with the community.
  - Some physicians demanded that some topics in genetics should be added in the curriculum of secondary school students.
  - Some suggested the youth population as the best target for health education.
  - The majority suggested the mothers to be the best target for genetic health education.

### Seminars for the physicians:

- ❖ Title: Genetics and the future of our children: Possible solutions

- ❖ Topics:
  - Approach to common genetic problems.
  - Current genetic services in Egypt.
  - Genetic and congenital disorders: possible ways of prevention and early intervention.
- ❖ Target audience: 25 physicians from El-Hawamdeya city in each seminar.
- ❖ Setting:
  - Sugar company medical center.
  - Physicians syndicate club.

### **Curriculum for training nurses and community outreach visitors on genetic health education:**

A manual was prepared to provide the COV with simple information in genetics about heredity, some preventable genetic and congenital disorders, and simple practical ways of prevention and intervention so that it could help them in delivering the prepared health messages to the community.

Contents of the manual:

1. Definitions and terminology
2. The cell, the chromosome, and the DNA
3. Modes of inheritance
4. Genetic diseases caused by chromosomal abnormalities:
  - a) Down syndrome
  - b) Turner syndrome
5. Autosomal recessive disorders:
  - a) Thalassemia
  - b) Phenylketonuria
6. Autosomal dominant disorders:
  - a) Achondroplasia
7. Sex linked disorders:
  - a) G6PD deficiency
  - b) Hemophilia
8. Multifactorial inheritance:
  - a) Breast cancer
  - b) Diabetes
  - c) Hypertension
9. Congenital anomalies:
  - a) Cleft lip and palate
  - b) Neural tube defect
  - c) Congenital rubella syndrome
  - d) Congenital toxoplasmosis
10. Prevention and early detection of congenital and genetic disorders

### **Raising Community Awareness in the Field of Prevention of Genetic & Congenital Disorders: Simplified Health Messages**

For the purpose of raising community awareness in the field of prevention of genetic and congenital disorders, we have designed illustrative and simple health messages in bright colours cartoon sketches that would be most suitable for that community. Sixteen drawings were designed and gathered in a small educational flip chart on a story of a young couple, starting family life and dreaming of getting healthy children. Through their journey health messages were inserted at each step; premarital, before getting pregnant, during pregnancy and after delivery.



Some information about birth defects, chromosomal and genetic disorders, including the risk of consanguinity and parents' age were also added. Finally, where to seek advices for genetic disorders, starting at primary health care units up to the highly specialized university centers.

### **COV training:**

- ❖ Before training the outreach visitors we first performed 2 orientation courses for the PHC physicians in Om-Khenan PHC center and the genetic counseling clinic in Giza, to prepare them for the expected new patients and families from Om-Khenan village who will be coming to the clinics to ask for services. We wanted them to know that credibility is the most important thing in that kind of activities.
- ❖ 4 PHC physicians were selected and assigned to do daily supervision on the OV during their HE sessions, so those 4 physicians attended the COV training as well.
- ❖ Training course for COV lasted for 3 weeks and it took exactly 16 days. It include theoretical training on the prepared curriculum and then on the health messages. Practical training included role play and on job training. We also trained them on how to apply the evaluation test, and giving them important instructions on how to approach the community and how to respond to questions. A pre and post training test was also performed.

### **Community education:**

- ❖ Health education sessions for 500 women through home visits took exactly 42 days within 9 weeks duration, 6 COVs accomplished the fieldwork, each one of them visited about 84 women, 2 women/ day. The session took 30-45 minutes with the application of the pre and post HE evaluation questionnaire it took an extra 10 to 15 minutes.
- ❖ Local Supervision on HE sessions was done on a daily basis by the selected 4 PHC physicians and central supervision on a weekly basis by one of us.
- ❖ 4 seminars were conducted and were attended by women coming to receive services in the PHC center of Om-Khenan they were gathered and HE using the materials that we prepared was done by 2 COVs and 2 trained nurses.

### **Pre and post health education evaluation test:**

#### **Scoring system:**

For the knowledge items, a correct response was scored 1 and the incorrect zero. For each area of knowledge, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into a percent score, and means and standard deviations were computed. Knowledge was considered satisfactory if the percent score was 50% or more and unsatisfactory if less than 50%.

Tables 1-8 represent categorical analysis, where each person's score was dichotomized to either "satisfactory (50%+)" or "unsatisfactory (<50%)" according to the total score he/she attained at the pre and posttests. They indicate improvement in most questions and all areas. Overall, table 8 demonstrates that none of the respondents had a satisfactory level of knowledge (none attained a total score of 50% or higher) at the pretest. At the posttest, 97.5% had satisfactory knowledge.

Table 9 is a quantitative comparison of the knowledge scores in each area after being converted into a percent score. For example, in the family planning area, the mean score of the group at the pretest was 43.19 out of a total score of 100, which

means that they attained less than half of the correct maximum score. At the posttest, the score increased to 76.87 out of a total score of 100. This shows that the score improved, and the difference was statistically significant.

Table 1. Pre-post intervention knowledge of participants regarding family planning

| Satisfactory knowledge (50%+) about: | Time           |      |                 |      | X <sup>2</sup><br>Test | p-value |
|--------------------------------------|----------------|------|-----------------|------|------------------------|---------|
|                                      | Pre<br>(n=488) |      | Post<br>(n=488) |      |                        |         |
|                                      | No.            | %    | No.             | %    |                        |         |
| Family planning:                     |                |      |                 |      |                        |         |
| ▪ Basis of happy family              | 31             | 6.4  | 395             | 80.9 | 551.93                 | <0.001* |
| ▪ Importance of planning             | 476            | 97.5 | 480             | 98.4 | 0.82                   | 0.37    |
| <b>Total for family planning</b>     | 332            | 68.0 | 483             | 99.0 | 169.60                 | <0.001* |

Table 2. Pre-post intervention knowledge of participants regarding premarital counseling

| Satisfactory knowledge (50%+) about:   | Time           |     |                 |      | X <sup>2</sup><br>Test | p-value |
|--|----------------|-----|-----------------|------|------------------------|---------|
|  | Pre<br>(n=488) |     | Post<br>(n=488) |      |                        |         |
|  | No.            | %   | No.             | %    |                        |         |
| Premarital genetic counseling:         |                |     |                 |      |                        |         |
| ▪ Proper time                          | 6              | 1.2 | 7               | 1.4  | 0.08                   | 0.78    |
| ▪ Procedures                           | 33             | 6.8 | 436             | 89.3 | 666.62                 | <0.001* |
| <b>Total for premarital counseling</b> | 2              | 0.4 | 308             | 63.1 | 442.65                 | <0.001* |

Table 3. Pre-post intervention knowledge of participants regarding consanguinity

| Satisfactory knowledge (50%+) about: | Time           |      |                 |      | X <sup>2</sup><br>Test | p-value |
|--------------------------------------|----------------|------|-----------------|------|------------------------|---------|
|                                      | Pre<br>(n=488) |      | Post<br>(n=488) |      |                        |         |
|                                      | No.            | %    | No.             | %    |                        |         |
| Consanguinity:                       |                |      |                 |      |                        |         |
| ▪ Family pedigree                    | 149            | 30.5 | 482             | 98.8 | 497.15                 | <0.001* |
| ▪ Consanguineous marriage            | 178            | 36.5 | 481             | 98.6 | 428.93                 | <0.001* |
| <b>Total for consanguinity</b>       | 87             | 17.8 | 476             | 97.5 | 635.17                 | <0.001* |

Table 4. Pre-post intervention knowledge of participants regarding normal pregnancy

| Satisfactory knowledge (50%+) about:                  | Time        |      |              |      | X <sup>2</sup> Test | p-value |
|---|-------------|------|--------------|------|---------------------|---------|
|   | Pre (n=488) |      | Post (n=488) |      |                     |         |
|   | No.         | %    | No.          | %    |                     |         |
| Normal pregnancy & antenatal care:                    |             |      |              |      |                     |         |
| ▪ Planning for pregnancy and preconception counseling | 2           | 0.4  | 446          | 91.4 | 813.40              | <0.001* |
| ▪ Folic acid supplementation                          | 25          | 5.1  | 481          | 98.6 | 853.36              | <0.001* |
| ▪ Nutrition in pregnancy                              | 269.        | 55.1 | 480          | 98.4 | 255.57              | <0.001* |
| ▪ Things to avoid                                     | 24          | 4.9  | 465          | 95.3 | 797.06              | <0.001* |
| <b>Total for normal pregnancy</b>                     | 2           | 0.4  | 472          | 96.7 | 906.07              | <0.001* |

(\*) Statistically significant at  $p < 0.05$

Table 5. Pre-post intervention knowledge of participants regarding infectious diseases affecting pregnancy

| Satisfactory knowledge (50%+) about:       | Time        |      |              |      | X <sup>2</sup> Test | p-value |
|--|-------------|------|--------------|------|---------------------|---------|
|  | Pre (n=488) |      | Post (n=488) |      |                     |         |
|  | No.         | %    | No.          | %    |                     |         |
| Infections and pregnancy:                  |             |      |              |      |                     |         |
| ▪ Rubella and vaccine                      | 2           | 0.4  | 401          | 82.2 | 672.88              | <0.001* |
| ▪ Toxoplasmosis and cats                   | 67          | 13.7 | 482          | 98.8 | 717.04              | <0.001* |
| ▪ Uncooked food risks                      | 59          | 12.1 | 479          | 98.2 | 730.62              | <0.001* |
| <b>Total for Infections and pregnancy:</b> | 6           | 1.2  | 482          | 98.8 | 928.59              | <0.001* |

(\*) Statistically significant at  $p < 0.05$

Table 6. Pre-post intervention knowledge of participants regarding genetic/congenital; diseases in pregnancy

| Satisfactory knowledge (50%+) about:                                    | Time        |     |              |      | X <sup>2</sup> Test | p-value |
|---|-------------|-----|--------------|------|---------------------|---------|
|   | Pre (n=488) |     | Post (n=488) |      |                     |         |
|   | No.         | %   | No.          | %    |                     |         |
| Genetic/congenital diseases/Possible prevention and early intervention: |             |     |              |      |                     |         |
| ▪ Neonatal thyroid screening  | 21          | 4.3 | 482          | 98.8 | 871.81              | <0.001* |
| ▪ Down syndrome (DS)  | 6           | 1.2 | 485          | 99.4 | 940.37              | <0.001* |
| ▪ DS risk & early intervention  | 2           | 0.4 | 478          | 98.0 | 928.84              | <0.001* |
| ▪ Turner syndrome   | 1           | 0.2 | 476          | 97.5 | 925.16              | <0.001* |
| ▪ Thalassemia   | 0           | 0.0 | 417          | 85.5 | 728.07              | <0.001* |
| ▪ G6PD deficiency   | 22          | 4.5 | 484          | 99.2 | 875.96              | <0.001* |
| ▪ Food/drugs restricted in G6PD def.                                    | 31          | 6.4 | 484          | 99.2 | 843.60              | <0.001* |
| <b>Total for genetic/congenital diseases:</b>                           | 0           | 0.0 | 482          | 98.8 | 952.29              | <0.001* |

Table 7. Pre-post intervention knowledge of participants regarding genetic counseling

| Satisfactory knowledge (50%+) about: | Time        |      |              |      | X <sup>2</sup> Test | p-value |
|--------------------------------------|-------------|------|--------------|------|---------------------|---------|
|                                      | Pre (n=488) |      | Post (n=488) |      |                     |         |
|                                      | No.         | %    | No.          | %    |                     |         |
| Genetic services:                    |             |      |              |      |                     |         |
| ▪ Proper time                        | 26          | 5.3  | 444          | 91.0 | 717.06              | <0.001* |
| ▪ Periodic checkup                   | 27          | 5.5  | 482          | 98.8 | 850.04              | <0.001* |
| ▪ Action in case of suspicion        | 307         | 62.9 | 480          | 98.4 | 196.38              | <0.001* |
| ▪ Service settings                   | 12          | 2.5  | 389          | 79.7 | 601.62              | <0.001* |
| <b>Total for genetic services</b>    | 7           | 1.4  | 459          | 94.1 | 839.02              | <0.001* |

(\*) Statistically significant at  $p < 0.05$

Table 8. Total pre-post intervention knowledge of participants

|                         | Time        |       |              |      | X <sup>2</sup> Test | p-value |
|-------------------------|-------------|-------|--------------|------|---------------------|---------|
|                         | Pre (n=488) |       | Post (n=488) |      |                     |         |
|                         | No.         | %     | No.          | %    |                     |         |
| Total knowledge:        |             |       |              |      |                     |         |
| ▪ Satisfactory (50%+)   | 0           | 0.0   | 476          | 97.5 |                     |         |
| ▪ Unsatisfactory (<50%) | 488         | 100.0 | 12           | 2.5  | 929.15              | <0.001* |

(\*) Statistically significant at  $p < 0.05$

Table 9. Pre-post intervention knowledge scores of participants

| Knowledge scores (%)           | Time        |              | Mann Whitney Test | p-value |
|--------------------------------|-------------|--------------|-------------------|---------|
|                                | Pre (n=488) | Post (n=488) |                   |         |
| Family planning:               |             |              |                   |         |
| Mean                           | 43.19       | 76.87        |                   |         |
| SD                             | 14.78       | 17.98        | 534.74            | <0.001* |
| Median                         | 50.00       | 75.00        |                   |         |
| Premarital genetic counseling: |             |              |                   |         |
| Mean                           | 20.16       | 47.70        |                   |         |
| SD                             | 8.66        | 12.27        | 630.38            | <0.001* |
| Median                         | 25.00       | 50.00        |                   |         |
| Consanguinity:                 |             |              |                   |         |
| Mean                           | 22.54       | 77.27        |                   |         |
| SD                             | 25.85       | 17.20        | 601.95            | <0.001* |
| Median                         | 0.00        | 66.70        |                   |         |
| Normal pregnancy:              |             |              |                   |         |
| Mean                           | 11.66       | 74.06        |                   |         |
| SD                             | 10.98       | 14.86        | 740.54            | <0.001* |
| Median                         | 10.00       | 70.00        |                   |         |
| Infections and pregnancy:      |             |              |                   |         |
| Mean                           | 5.90        | 82.30        |                   |         |
| SD                             | 13.30       | 14.54        | 794.99            | <0.001* |
| Median                         | 0.00        | 80.00        |                   |         |
| Genetic/congenital diseases:   |             |              |                   |         |

|                   |       |       |        |         |
|-------------------|-------|-------|--------|---------|
| Mean              | 1.42  | 74.19 | 796.12 | <0.001* |
| SD                | 4.57  | 16.87 |        |         |
| Median            | 0.00  | 69.20 |        |         |
| Genetic services: |       |       | 716.79 | <0.001* |
| Mean              | 18.36 | 75.84 |        |         |
| SD                | 11.57 | 18.24 |        |         |
| Median            | 16.65 | 77.80 |        |         |
| Total knowledge:  |       |       | 732.40 | <0.001* |
| Mean              | 13.85 | 70.21 |        |         |
| SD                | 5.90  | 13.12 |        |         |
| Median            | 13.20 | 67.90 |        |         |

(\*) Statistically significant at  $p < 0.05$

### Feedback from clients and providers:

#### ❖ Clients:

1. Client satisfaction
2. Opinion on the prepared materials
3. More HE in the field of genetics & involvement of other clients.

#### ❖ COV:

1. Comparison to other HE activities in other programs in terms of relevance, acceptance and value to the local community.
2. Sustainability
3. Opinion on prepared materials

### Outcome:

- ❖ Increase referral from El-Hawamdya city to the genetic counseling clinic
- ❖ 12 were referred from Om-Khenan PHC center:
  - a. 3 couples for premarital genetic counseling
  - b. 6 infants and children with cong. & genetic disorders:  
Developmental delay, Down syndrome, multiple congenital anomalies, Thalassemia, MPS.
  - c. 3 newborns with birth defects:  
Down syndrome, skeletal dysplasia, hypospadias

### Short term plan:

- ❖ Genetic HE Seminars for:
  1. PHC physicians
  2. Community leaders
  3. Local community in Om-Khenan + Other villages
  4. Secondary school students
- ❖ Designing other educational materials

### Long term plan:

- ❖ Extend education to other families and other family members in Om-Khenan village.
- ❖ Coordination with other organizations and health authorities to extend the module for community genetic education to other villages.
- ❖ Follow-up with target families to detect changes in attitude and practice.
- ❖ Sustain networking and sharing deliverables.
- ❖ Upgrading and expanding genetic services at the PHC level.