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cc: J. L. Bosch
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Dr. Uemura, Second Back Translation

Agenda 1

(Study Proposal)

Member of HUI developing study committee in Japan

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1. Members required (condition required)

Will recruit working group with economical and econometric back ground.

2. Current status of Japanese version HUI

Changed according to the comments from McMaster group on the first back translation.

3 session were made (with 4-5 person. 21-45 years old) to examine "Japanese"

3. Objectives (Study population) ?

How many field,

Characteristics of field,

Number of objectives,

Range of ages,

Occupations,

Directors

etc

4. Which HUI ?

We translated HUI2,3. And we translated HUI2,3SU15Q, too. We guess HUI2,3 will be best choice for our survey

Agenda 2

(Political Issue)

8. Other Japanese researchers interested in HUI

- We aware of Dr. Hisashige presented his research of utility measurement using HUI2. We, I and Johanna asked him about his status with master group by fax mail but no reply. We tried to talk with him about this matter on November last year at Keio University on one study meeting but our discussion ended very soon due to his lack of time and we have not heard anything from him anymore. We have to ask and clear about this kind of matter. We have to co-operate or compete.

9. Conditions suggested by McMaster group

- Access of Public Sector and Not-for-Profit Private Sector Researchers to HUI Materials in Japan.
 - 1: To cope with the requirements of public sector funding in Japan.
 - Agree that public sector and not-for-profit firms in Japan would have access to the use of copyrighted Japanese HUI materials such as the questionnaires without being required to pay a fee to the HUI Group, subject to several conditions.
 - Agree to waive the fee for specified applications as defined by outline for access to copyrighted material in Japanese for which the translations were supported by the Ministry of Health and Welfare in Japan.
 - 2: Basic Policy toward the copyright
 - First, the distribution of such materials would be conducted by a group in Japan (presumably your group at Keio).
 - Second, the group in Japan would have the responsibility for obtaining signed agreements from such users in Japan. The signed agreements would grant permission for the use of HUI one study at a time and users would state that users would not distribute the copyrighted materials to others.
 - Third, the group in Japan would be able to levy nominal charges to cover the direct cost of distributing materials (time and materials).
 - Fourth, the group in Japan would be responsible for maintaining a registry of users who have been granted permission to use the translated Japanese HUI materials.

- **Fifth**, the group in Japan would be responsible for **reporting** to the HUI Group on the name of the user, name of the study, questionnaire being used, and expected **completion date** of study on a **quarterly basis**.
- **Sixth**, the group in Japan would have the responsibility for updating materials as needed. (On occasion we revise HUI materials in English; it would be important to make the corresponding changes in the Japanese versions. Normally these changes are quite modest.)
- **Seventh**, such an agreement between the HUI Group and the group in Japan would be **limited in duration with provisions for renewal**. Clearly the group in Japan would have to be "defined".
- **3:Definitions for public sector and not-for-profit organizations**
- Agree with the criteria for not-for-profit organizations that you outlined, namely that the organization conducting the research be not-for profit and that the research is being funded by a not-for-profit organization. Thus research done at universities under the sponsorship of pharmaceutical firms would not qualify.
 - Consulting on other than Not-for-Profit Research Studies in Japan.
- The HUI Group would distribute HUI materials to for-profit users such as pharmaceutical firms, or to users doing studies sponsored by for-profit organizations. When the HUI Group provides copies of Japanese versions of HUI materials translated by the Keio group to such users, the HUI Group would share revenues with the Keio group.
 - Consulting Services.
- The HUI Group and the Keio Group would be free to charge for consulting services and expertise on the assessment of health-related quality of life and economic evaluation of health-care services.

10. Conditions suggested by group in Japan (Keio Group)

- Access of Public Sector and Not-for-Profit Private Sector Researchers to HUI Materials in Japan.

- **1: To cope with the requirements of public sector funding in Japan,**

Most brief and ideal means of settling the concerns of founding sector would be Japanese HUI and its tariff comes out in **public domain**. But I understand it would be against the basic policy of HUI distribution. Regarding to the point of view, we suggested as below;

- **Insist that public sector such as local government (3500 of self-governing bodies in Japan could be expected to use HUI materials) and not-for-profit firms should have access to the use of copyrighted Japanese HUI materials easily such as the questionnaires without being required to pay a fee to the HUI Group.**

- **Insist that HUI Group and Keio Group should waive the fee for specified applications as defined by outline for access to copyrighted material in Japanese for which the translations were supported by the Ministry of Health and Welfare in Japan.**

- **2: Basic Policy toward the copyright**

- **First, We agree** the distribution would be conducted by us. But we have to be careful that such system would not to prevent easy access by anyone who need to use it.

- **Second, We can** obtain signed agreements from such users in Japan. But **we afraid** that such system would be too much strict (as the signed agreements would grant permission for the use of HUI one study at a time and users would state that users would not distribute the copyrighted materials to others). Our concern about this policy is first, Difficulty for the practitioner to access HUI materials, second, some different way of understanding toward the intellectual proprietary between Japan and Western country.

- **Third, We agree** and appreciate we can levy nominal charges to cover the direct cost of distributing materials (time and materials). But **we have to strictly distinguish the direct cost, revenues and coverage of the public foundation, as long as we receive public grant.**

- **Fourth, we can maintain a registry of users** who have been granted permission to use the materials. But as I mentioned above, we have to care such system prevent easy access.

- **Fifth, we disagree that we report** to the HUI Group on the name of the all user, name of the all studies. We could report the data of such major studies as we collaborate intensively or your specified requirements. And we believe it would depend on how minute the report could be that we are expected to report **completion date** of study on a **quarterly basis**. I repeat we have to care such system prevent easy access.

- **Sixth, we do** the necessary update by requirement from HUI Group. We hope such changes are quite modest.

- **Seventh, we understand** that such an agreement between the HUI Group and us would be **limited in duration with provisions for renewal**. This is routine expression in contract. We hope you won't quit our basic agreement and won't introduce drastically new policy in near future. We, Group in Japan, are very close friends, so clearly can be "defined".

Have to be discussed intensively.....

- **3: Difinitions for public sector and not-for-profit organizations**
- **We can outline** with the criteria for not-for-profit organizations. Namely that the organization conducting the research be not-for profit and that the research is being funded by a not-for-profit organization. Thus research done at universities under the sponsorship of pharmaceutical firms would not qualify.
 - **Consulting on other than Not-for-Profit Research Studies in Japan.**
- **We agree** that HUI Group would distribute HUI materials to for-profit users such as pharmaceutical firms, or to users doing studies sponsored by for-profit organizations. **But your mentioned policy and expression toward the fee for intellectual proprietary** "When the HUI Group provides copies of Japanese versions of HUI materials translated by the Keio group to such users, the HUI Group would share revenues with the Keio group."cannot clear the condition and against the rules for government grant delivery.
 - **Consulting Services.**
- **Relating to above concern, any kinds of for-profit-activities based on the products comes after study are strictly limited, nearly prohibited as long as public foundation are invested in it.** So your mentioned policy and expression would prevent us from receiving public grant of ministry of health and welfare."The HUI Group and the Keio Group would be **free to charge** for consulting services and expertise on the assessment of health-related quality of life and economic evaluation of health-care services."

I am afraid we would mistake the means for the end ,because we are asking you to alter your basic policy for HUI distribution, according to our conditions and rules to receive public grants. I assume Best thing, scholastically, would be that we, group in Japan should take after the experiences that another country where translated HUI was developed. But I also can say, just within the matter we are now facing, that all concern from public sector of national foundation will clear if you permit us to publish Japanese version of HUI questionnaire in public domain and abandon copyright just in Japanese version.

These several lines above are not for forward to MHW. As I assume, we **can discuss and device some other policy with which both of your policy and MHW founding policy can go well.**

As you wrote, we think that the alternative arrangements will achieve the **same objectives** and comply with the requirements of our public sector funding agencies.

5. When will Canadian tariff of HUI Mark3 be published ?

We have to know whether we will be able to adopt Canadian tariff to our data at the end of our field work.

6. Using Japanese HUI questionnaire with the Canadian tariff ?

General populations

HUI questionnaire in a health survey using Canadian tariff. Is it possible to compare the results with the Canadian population? We have to ask your status of view whether data of the Canadian population is available for such a comparison.

Clinical application for evaluating health status of some specific disease, tentatively we plan

- 1, Patients with ischemic heart disease
- 2, Patients with aortic disease
- 3, Patients with various stage of hepatitis
- 4, Patients with peripheral arterial occlusive disease

and compare results with other QOL instruments and with the outcomes of comparable studies performed in the Netherlands and US (JL Bosch)

5,

6,

Clinical application for evaluating the outcome of medical technologies

- 1, PTCA
- 2, CABG
- 3, Interferon for hepatitis

4,

5,

7. Conduct a study to assess the Japanese tariff ?

This would be very taking-time study. We have to ask the basic methods to develop the own tariff. Is it possible for us to arrange the Canadian tariff according to the comparison with the Canadian tariff? Or should we perform another TTO, SG, or VAS study in order to develop Japanese tariff? And how we can cope with such a complicated procedure ?

HUI Mark III

順翻訳

自己記入式健康度調査質問票

記入方法

この質問票はあなたのふだんの健康に関してお尋ねするものです。いくつかの質問に関して、あなたに当てはまらないと感じられるかも知れません。しかし皆さんに対して同じ質問をすることが大切である点をご理解下さい。

各質問を読んで、回答を慎重に考えて下さい。各質問に対してあらかじめ設けられた答えのうち、あなたのふだんの生活上、できる事やできない事を一番よく言い表していると思われるものをひとつ選択して下さい。

選択した答えの文頭文字に○をつけて下さい。

内容の似かよった質問も若干あるかとは思いますが、それぞれについて回答して下さい。
ご協力ありがとうございます。

質問

1. ふだんあなたが新聞を読む能力は、以下に述べるもののうちどれが一番当てはまりますか？
ひとつ選んで下さい。

- a. 眼鏡やコンタクトレンズなしでも十分に読める。
- b. 眼鏡やコンタクトレンズがあれば十分に読める。
- c. 眼鏡やコンタクトレンズがあっても十分に読む事ができない。
- d. まったく見えない。

2. ふだんあなたが、通りの反対側にいる友達を認識する能力は、以下に述べるもののうちどれが一番当てはまりますか？ひとつ選んで下さい。

- a. 眼鏡やコンタクトレンズなしでも十分にわかる。
- b. 眼鏡やコンタクトレンズがあれば十分にわかる。
- c. 眼鏡やコンタクトレンズがあってもはっきりとわからない。
- d. まったくみえない。

3. ふだんあなたが、3人以上の人達との会話内容を聞き取る能力は、以下に述べるもののうちどれが一番当てはまりますか？ひとつ選んで下さい。

- a. 補聴器なしでも会話内容を聞き取れる。
- b. 補聴器があれば会話内容を聞き取れる。
- c. 補聴器があっても会話内容を聞き取る事ができない。
- d. 会話内容を聞き取れない、しかし補聴器も着けていない。
- e. まったく聴こえない。

4. ふだんあなたが、静かな部屋の中で相手の話す内容を聞き取る能力は、以下に述べるものうちどれが一番当てはまりますか？ひとつ選んで下さい。

- a. 補聴器なしでも会話内容を聞き取れる。
- b. 補聴器があれば会話内容を聞き取れる。
- c. 補聴器があっても会話内容を聞き取る事ができない。
- d. 会話内容を聞き取れない、しかし補聴器も着けていない。
- e. まったく聴こえない。

5. ふだんあなたが、知らない人と会話し自分の話した内容を理解してもらう場合、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 完全に話を理解してもらえる。
- b. 部分的には話を理解してもらえる。
- c. 話を理解してもらえない。
- d. まったく話をする事ができない。

6. ふだんあなたが、知り合いと会話し自分の話した内容を理解してもらう場合、以下に述べるもののうちどれが一番よく当てはまりますか？ ひとつ選んで下さい。

- a. 完全に話を理解してもらえる。
- b. 部分的には話を理解してもらえる。
- c. 話を理解してもらえない。
- d. まったく話をする事ができない。

7. ふだんのあなたの感情は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 幸せで、人生に対して関心が持てる。
- b. やや幸せ。
- c. やや不幸。
- d. とても不幸。
- e. 不幸すぎて生きる意義を失っている。

8. ふだんのあなたの痛みや不快感の程度は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 痛みや不快感がまったくない。
- b. 多少の痛みはあるが、活動は妨げられない。
- c. 若干の痛みがあり、活動がわずかに妨げられる。
- d. かなりの痛みがあり、活動がいくらか妨げられる。
- e. ひどい痛みがあり、活動のほとんどが妨げられる。

9. ふだんのあなたの歩行能力は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

注：歩行器具とは、副木、杖、松葉杖、歩行器などの補助用具を指します。

- a. 歩行器具なしに難なく近所を歩き回る事ができる。
- b. 近所を歩き回るのは困難だが、歩行器具や他人の介助を必要としない。
- c. 歩行器具を必要とするが、他人の介助なしに近所を歩き回る事ができる。
- d. ほんの短い距離であれば歩行器具を使って歩く事ができ、かつ車椅子なら近所に出あるく事ができる。
- e. 歩行器具を用いても一人では歩けない。少し歩くのにもだれかの介助が必要で近所に出あるくには車椅子が必要である。
- f. まったく歩けない。

10. ふだんあなたの手や指を動かす能力は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

注：特別な道具とは、手指の不自由を補うための道具、例えば衣服のボタン掛けの留金とか、ジャーを開けたり小物をつかむ器具などを指します。

- a. 両手十指を完全に使いこなせる。
- b. 手指の不自由はあるが、特別な道具や他人の介助を必要としない。
- c. 手指の不自由があるが、特別な道具を使えば他人の介助を要しない。
- d. 手指の不自由があり、特別な道具を用いても他人の介助を必要とする事がある。
- e. 手指の不自由があり、特別な道具を用いてもほとんどの場合、他人の介助が必要である。
- f. 手指が不自由で、（特別な道具を用いても）何をするにも他人の介助を必要とする。

11. ふだんあなたの、物事の記憶力は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. ほとんどの事を思い出す事ができる。
- b. やや忘れっぽい。
- c. 大変忘れっぽい。
- d. まったく何も思い出す事ができない。

1 2. ふだんあなたが、日々の問題を考え解決していく能力に関は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 日々問題をはっきりと考え解決することができる。
- b. 日々問題を考え解決するには、わずかに困難がある。
- c. 日々問題を考え解決するには、いくらか困難がある。
- d. 日々問題を考え解決するには、相当困難がある。
- e. 日々問題を考え解決することが、まったくできない。

1 3. ふだんあなたが身の回りのことをする能力は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 食事、入浴、着替え、トイレが普通にできる。
- b. 多少の困難はあるが自力で食事、入浴、着替え、トイレができる。
- c. 自力で食事、入浴、着替え、トイレをするには補助器具を必要とする。
- d. 食事、入浴、着替え、トイレに他人の介助を必要とする。

1 4. ふだんのあなたの感情は、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 大体幸せで、取りたてて心配事がない。
- b. 時折苛立ったり、怒ったり、しゃくにさわったり、不安になったり落ち込んだりする。
- c. しばしば苛立ったり、怒ったり、しゃくにさわったり、不安になったり落ち込んだりする。
- d. ほとんどいつも苛立ったり、怒ったり、しゃくにさわったり、不安になったり落ち込んだりしている。
- e. 極度に苛立ったり、怒ったり、しゃくにさわったり、不安になったり落ち込んだりして、よく入院や精神病院受診を必要とする。

1 5. ふだんあなたの痛みの程度に関し、以下に述べるもののうちどれが一番当てはまりますか？ ひとつ選んで下さい。

- a. 痛みや不快感がまったくない。
- b. 時折痛みがある。不快感は市販薬や自己管理によって和らげられ、普通の活動の妨げとはならない。
- c. しばしば痛みがある。不快感により普通の活動が妨げられることもあるが、飲み薬によって和らげられる。
- d. しばしば痛みがある；普通の活動がしばしば妨げられ、和らげるためには麻酔薬などの処方が必要とする。
- e. ひどい痛みがある。痛みは薬では和らげられず、常に普通の活動が妨げられる。

HUI MarkⅢ

逆翻訳

Self-Administered Questionnaire for a Health Status Survey

How to fill out the questionnaire:

The questions below concern your everyday health. While some questions may not apply to you, please understand that it is important to ask the same questions of all of you.

Please read the questions and consider them carefully before answering. Please choose one answer that is most applicable to your everyday activities, and circle its letter.

Even if some questions appear similar, please answer all questions.

Thank you for your cooperation.

Questions:

1. How well can you read a newspaper? Please circle the letter of the answer that best applies to you.

- a. I can read a newspaper without glasses or contact lenses.
- b. I can read a newspaper if I use glasses or contact lenses.
- c. I have difficulty reading a newspaper even if I use glasses or contact lenses.
- d. I am completely unable to read a newspaper.

2. How well can you recognize a friend across a road? Please circle the letter of the answer that best applies to you.

- a. I can recognize him/her definitely without glasses or contact lenses.
- b. I can recognize him/her definitely if I use glasses or contract lenses.
- c. I am definitely unable to recognize him/her even if I use glasses or contact lenses.
- d. I am completely unable to recognize him/her.

3. How well can you hear what three or more persons are saying? Please circle the letter of the answer that best applies to you.

- a. I can hear what they are saying without a hearing aid.
- b. I can hear what they are saying if I use a hearing aid.
- c. I am unable to hear what they are saying clearly even if I use a hearing aid.
- d. I am unable to hear what they are saying clearly, but I don't use a hearing aid.
- e. I am completely unable to hear what they are saying.

4. How well can you hear what someone is saying in a quiet room? Please circle the letter of the answer that best applies to you.

- a. I can hear what he/she is saying without a hearing aid.
- b. I can hear what he/she is saying if I use a hearing aid.
- c. I am unable to hear what he/she is saying clearly even if I use a hearing aid.
- d. I am unable to hear what he/she is saying clearly, but I don't use a hearing aid.
- e. I am completely unable to hear what he/she is saying.

5. When you talk with someone you don't know, how well do you think he/she can understand what you say? Please circle the letter of the answer that best applies to you.

- a. He/she can understand what I say completely.
- b. He/she can understand somewhat.
- c. He/she can't understand what I say very well.
- d. I am completely unable to communicate verbally with him/her.

6. When you talk with somebody you know, how well do you think he/she can understand what you say? Please circle the letter of the answer that best applies to you.

- a. He/she can understand what I say completely.
- b. He/she can understand somewhat.
- c. He/she can't understand what I say very well.
- d. I am completely unable to communicate verbally with him/her.

7. How do you usually feel about your daily life? Please circle the letter of the best answer.

- a. I'm happy, and I am able to have hobbies and interests.
- b. I'm fairly happy.
- c. I'm not happy.
- d. I'm very unhappy.
- e. I'm extremely unhappy and have lost my will to live.

8. How much pain and/or discomfort do you usually experience? Please circle the letter of the answer that best applies to you.

- a. I don't feel any pain or discomfort at all.
- b. I feel some pain, but it doesn't impair my daily activities.
- c. I feel mild pain, but it rarely impairs my daily activities.
- d. I feel severe pain, and it sometimes impairs my daily activities.
- e. I feel very severe pain, and it almost always impairs my daily activities.

9. How well can you walk? Please circle the letter of the answer that best applies to you.

Note: "Self-help walking devices" refers to devices such as a splint, walking stick, crutch, or walker.

- a. I am able to walk around near my house with no need for self-help walking devices.
- b. It's difficult for me to walk around near my house, but I don't need self-help walking device or someone's help.
- c. I am able to walk around near my house without help, although I do need a self-help walking device.
- d. I am able to walk around with the help of a self-help walking device within a limited range, and I am able to move around near my house with an aid of wheelchair.
- e. I am unable to walk alone even if I use a self-help walking device. I need someone's help to walk, and a wheelchair when I go out of the house.
- f. I am completely unable to walk .

10. How well can you move your hands or fingers? Please circle the letter of the answer that best applies to you.

note: "Special tools" mean tools that assist finger movements, e.g., buttoning a jacket, opening a jar, and grasping a small article.

- a. I am completely able to use all my fingers.
- b. I have some trouble using my fingers, but I don't need special tools or someone's help.
- c. I have some trouble using my fingers, but I don't need someone's help if I use a special tool.
- d. I have some trouble using my fingers, and I sometimes need someone's help even if I use a special tool.
- e. I have some trouble using my fingers, and I almost always need someone's help even if I use a special tool.
- f. I have trouble using my fingers, and I always need someone's help even if I use a special tool.

11. How well does your memory function in daily life? Please circle the letter of the answer that best applies to you.

- a. I can remember nearly every thing.
- b. I sometimes forget things.
- c. I forget many things.
- d. I remember nothing.

12. How much can you think and solve everyday problems? Please circle the letter of the answer that best applies to you.

- a. I am completely able to think and solve everyday problems.
- b. It's a little hard for me to think and solve everyday problems.
- c. It's sometimes hard for me to think and solve everyday problems.
- d. It 's very hard for me to think and solve everyday problems.
- e. I am completely unable to think and solve everyday problems.

13. How well can you perform everyday tasks? Please circle the letter of the answer that best applies to you.

- a. I am able to eat, bathe/shower, dress myself, and go to the toilet without help.
- b. I am able to eat, bathe/shower, dress myself, and go to the toilet without help, with slight difficulty.
- c. When I eat, bathe/shower, dress myself, and go to the toilet, I need a self-help assisting device.
- d. When I eat, bathe/shower, dress myself, and go to the toilet, I need someone's help.

14. What is your general state of mind? Please circle the letter of the answer that best applies to you.

- a. I'm almost always happy, and have no particular anxieties.
- b. I sometimes become upset, angry, irritated, anxious, and/or depressed.
- c. I often become upset, angry, irritated, anxious, and/or depressed.
- d. I almost always become upset, angry, irritated, anxious, and/or depressed.
- e. My anger, irritation, anxiety, and/or depression are constant, so that I need to be admitted to a hospital or a psychiatric clinic.

15. How much pain do you experience on a daily basis? Please circle the letter of the answer that best applies to you.

a. I experience no pain or discomfort at all.

b. I sometimes experience pain and/or discomfort that is relieved by commercially available drugs and self-management, but it doesn't impair my daily activities.

c. I often experience pain and/or discomfort that sometimes impairs my daily activities, but it is relieved by orally ingested medicine.

d. I often experience pain that occasionally impairs my daily activities and can only be relieved by prescription medicine such as narcotic analgesics.

e. I experience severe pain that can not be relieved by medication, and that always impairs my daily activities.