The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)

Administration Manual

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CONTENTS

Section 1: Introduction

1.1	The concept of quality of life in clinical research	3
1.2	The individual nature of quality of life	3
1.3	Judgment Analysis	4
1.4	The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)	4
1.5	Appropriate respondents and applications	5

Section 2: SEIQoL Administration

2.1	Administration	6
2.2	Administration procedure	6
2.3	Potential problems in administration	9

Section 3: Scoring the SEIQoL

3.1	Recording scores	10
3.2	Multiple regression analysis: The Policy PC Programme	10
3.3	Using the Policy PC Programme	11
3.4	Deriving SEIQoL outcome data	12
3.5	Presenting data	13

Section 4: Reliability of the SEIQoL

4.1	Cue elicitation	13
4.2	Cue levels	14
4.3	Judgment analysis of weights	14
4.4	The SEIQoL index	15

Section 5: Validity of the SEIQoL

5.1	Content validity	15
5.2	Construct validity	17
5.3	Relationship with other measures	18

Section 6: Studies using the SEIQoL

6.1	Individually defined quality of life in a healthy adult sample	19
6.2	Psychometric properties of Judgment Analysis in a healthy adult sample	20
6.3	Individual quality of life in the healthy elderly	21
6.4	Individual quality of life in patients undergoing total hip replacement surgery	22
6.5	Individual quality of life in a gastroenterology unit sample	23

References. 26

Important Note:
In order to derive scores using the SEIQoL you will require a statistical programme for conducting multiple-regression analysis. We have used the POLICY PC Programme - Software for Judgment Analysis which derives judgment policies from judgment analysis tasks. This, together with the reference manual, may be acquired from Executive Decision Services, P.O. Box 9102, Albany, New York 12209.

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SECTION 1: INTRODUCTION

1.1 The concept of quality of life in clinical research

Advances in the clinical sciences this century have resulted in an impressive range of diagnostic procedures, therapies, drugs and surgical techniques which have revolutionised the management of heretofore fatal conditions. In addition to being concerned about life expectancy, people are also concerned about the quality of their lives. Partly in response to the views of patients, assessment of patient Quality of Life (QoL) is becoming increasingly important in medicine, nursing and in the behavioural sciences. It has already become an important outcome variable in assessing the impact of disease, illness and treatment (Spilker, 1990; Walker and Rosser, 1993; Bowling 1991; O'Boyle, 1992).

QoL is a multi-dimensional construct and there are various approaches to its evaluation. The approach varies depending on the aims of the exercise. Health economists, for example, use techniques such as the QALY (Quality Adjusted Life Year), standard gamble and time-trade-off techniques in order to incorporate QoL measures into economic analysis and clinical trials. Clinical research has utilised standardised and disease specific measures, usually in the form of questionnaires, in order to determine the impact of disease and treatment on patients' QoL. One of the problems of conducting research in this area is that there is no single agreed definition of QoL nor is there a single 'gold standard' measurement technique. However, there is broad agreement that studies of health related QoL should include assessments of physical functioning, including somatic sensations such as physical symptoms and pain; psychological function including concentration and mood; social and sexual functioning and occupational status. Many researchers also assess patients' global satisfaction and the economic impact of the condition.

While QoL scales and questionnaires, as well as the methods of rating and analysing them, have been developed by assessing the QoL of individuals, the specific items and the response categories do not represent the free choice of individuals who are subsequently investigated using the scale. Furthermore, the measures will often have been standardised in samples other than those currently being assessed. Results are generally presented as group statistics and provide little or no data on the QoL of individual patients.

1.2 The Individual Nature of Quality of Life

> '..... when it comes to saying in what happiness consists, opinions differ, and opinion of the wise take it to be something obvious and familiar, like pleasure or money or eminence and there are various other views and often the same person actually changes his opinion. When he is ill he says it is his health, when he is hard up he has that it is money.'
>
> *Aristotle (384-322BC) Ethica Nichomachea*

A number of authors have highlighted the individual nature of QoL (O'Boyle et al., 1994). Cohen (1982) has proposed that persons are best viewed as lives lived with some degree of coherence; a human person is a life lived according to a human plan. It is the plan of life and the inter-related purposes of a person that give his or her life the unity and meaning it has. When pushed to say who we are, we reflect on our aims and upon the causes and principles with which we identify. We give an account of ourselves when we say what we did, are doing or intend to do with our lives.

Features of life can be judged by their effect on the life plan. Some are considered good while others are considered less so. Intelligence, stamina, mobility and good health contribute to the realisation of human plans. Features of life such as the pursuit of one's vocation, the practice of one's art, the enjoyment of one's special pleasures and talents are evidence that the life plan is being advanced. Some features of life, however, hinder or block the pursuit of a person's life plan: disease, illness, confinement to bed or to an institution, mental instability, fear and pain.

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A similar view expressed by Calman (1984) is that QoL is reflected in the differences between a person's hopes and expectations, and their present experience. It is therefore dependent on the individual's past experience, present life-style and his or her hopes and ambitions for the future. The gap between hopes and reality may be narrowed in two ways. In medicine, firstly, the patient's functioning can be improved through treatment such as surgery or drugs. Secondly, the patient may be helped to achieve more realistic expectations through informed understanding of the limitations of their situation and acceptance of the risks involved with treatment in relation to the expected benefits.

Assessing the quality of an individual's life will involve attention to some elements that can be valued by us all since they will tend to maximise the realisation of any life plan. However, since a person's experiences, ambitions and plans are individual to him or her, some elements will be important to a particular degree for a particular person. Most QoL questionnaires impose an external value system on individuals by using standard formats, questions and weights of various pre-selected components of QoL derived from grouped data. The relevance of these standardised questionnaires to the individual patient has not been addressed widely.

Specific goals or behaviours important to an individual's QoL are unlikely to be represented adequately by broad questions about physical mobility or general health. Apparently similar behaviours do not have the same significance for all individuals desiring to experience them, nor do events or functions necessarily retain the same salience for a given individual with the passage of time or indeed over the course of an illness. In assessing QoL, an individual should be given the opportunity to identify those areas which are important to him or her, indicate how well they are doing in each particular area, and judge the relative importance of each area to their overall QoL.

1.3 Judgment Analysis

Judgment Analysis (JA), also known as policy capturing, is a research method which has been widely used in studies of judgment and decision making. JA externalises the manner in which a person makes a judgment or decision - their 'judgment policy'- by using statistical methods to derive an algebraic model of the judgment process. The goal of JA is to quantify the relationships between a person's judgment and the information, or 'cues', used to make that judgment. The theoretical foundations for JA lie in Brunswik's lens model (Brunswick, 1956) and in Social Judgment Theory as developed by Hammond (Hammond et al., 1975; Brehmer and Joyce 1988). Therefore, JA differs from other methods of deriving algebraic judgment models such as multi-attribute utility theory, in that it is the only method that is based on firm theoretical premises about how people cope with complex problems requiring judgment (Stewart, 1988a).

JA can be used, not only to model the judgment or decision process, but also as an aid to such processes. It has been found particularly useful in externalising the basis for judgment when people lack insight into the reasons for their judgments. This is often the case in expert judgment and decision making.

1.4 The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)

Components of QoL measured by the SEIQoL

The SEIQoL is designed to measure three elements of QoL:

- Those aspects of life considered by the individual to be crucial to his/her QoL are elicited by means of a structured interview.
- Current functioning/satisfaction with each aspect is rated by the individual.
- The relative importance of each aspect of QoL is measured by deriving the weight the individual assigns to each in judging overall QoL.

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Propositions underlying the SEIQoL

- QoL is individual in nature. Those aspects of life which are important to one person may have little or no relevance for another. Therefore, the only valid means of assessing QoL is by self-report.

- An individual's judgment of their overall QoL is constructed from their assessment of their level of functioning/satisfaction in discrete domains of life which they consider to be important. Thus, a person's judgment of their QoL depends on their value system which, while generally stable over time, may change. The relative importance which a person attaches to particular aspects of life may change, for example, as they grow older, due to an illness or to some other change in their circumstances or their perception of their circumstances. The dynamic nature of the individual's QoL is central to our understanding of the concept.

- In judging QoL, a person evaluates each important aspect of his or her life in terms of its relationship to worst and best possible states. This yardstick will also be specific to the individual and will be influenced by a variety of factors including experience and expectations.

- Only the individual can validly judge his or her QoL. Assessment of QoL in health has been developed largely in the context of professional assessment of patients. Many measures of health status such as the Karnofsky Index (Karnofsky and Burchenal, 1949) and the QL-Index (Spitzer et al., 1981) require the physician to rate the patient. Our perspective is that only the individual concerned can provide a comprehensive account of his or her own QoL. Assessments by others such as physicians or carers will be necessary in certain cases such as Alzheimer's disease, mental retardation, vegetative states or in the case of young children. However, these are proxy assessments and must not be confused with the individual's own assessment. This view is supported by studies documenting low levels of concordance between individuals' ratings of their own QoL and the assessments of their QoL made by others including physicians (Jachuck et al., 1982; McCusker and Stoddard 1984; Magaziner et al., 1987; Pearlman and Uhlmann, 1988; Slevin et al.,1990).

1.5 Appropriate Respondents and Applications

Most existing measures of quality of life are health related in that they have been designed to assess the impact of illness and treatment on the quality of life of patients, or significant others related to the patient. They reflect a 'disease' model which is primarily concerned with the measurement of health status and the health outcome of treatment interventions and care (Spilker, 1990; Bowling, 1991). The SEIQoL, in contrast, is based on a phenomenological approach to the measurement of quality of life, in which the terms of reference are determined entirely by the individual. It may therefore be used for measuring the QoL of healthy individuals (Section 6 - Studies to date) and should be free from cultural bias, although this has not yet been investigated empirically.

The SEIQoL may be used with a variety of patient groups (see Section 6 - Studies to date) but its applicability may be limited in illnesses which impair cognitive functioning or motivational state. Successful completion of the SEIQoL requires, *inter alia*, insight into the factors which determine one's QoL, the ability to think abstractly, the ability to make judgments based on information presented in diagrammatic form, and the ability to provide ratings using vertical and horizontal visual analogue scales. Therefore, its use with patient in whom these abilities are impaired (Coen et al., 1993) may be problematic and may necessitate modification of the standard form of the SEIQoL or use of another respondent (care-giver, 'significant other'). In the latter case the estimate of QoL will be indirect and should be designated as such. A direct weighting technique derived from the SEIQoL has recently been used to measure QoL in patients with HIV/AIDS (Hickey et al., 1993).

To date, the SEIQoL has been used with respondents ranging in age from early twenties to early nineties. Johnson (1990) has shown that the elderly tend to use non-compensatory decision strategies in completing tasks similar to JA. This might have been expected to reduce the reliability and validity of the weights.

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No such problems were encountered with healthy elderly respondents (Section 6.3). Given the cognitive requirements of the task, as outlined above, the SEIQoL, in its present form, is unlikely to be suitable for children. We do not know what lower age limit applies, as the SEIQoL has not yet been administered to children or to adolescents.

The SEIQoL has been specifically devised as an individual measure. It can therefore be used in single-subject study designs and in within-subject study designs in which respondents act as their own controls. This does not preclude its application in between-subject comparisons, but the individual nature of the SEIQoL is necessarily compromised when data must be grouped, summarised or reduced to summary scores. For the purpose of group comparisons a global QoL score can be calculated.

SECTION 2: SEIQoL ADMINISTRATION

2.1 Administration

The SEIQoL is administered in the form of a semi-structured interview. The interviewer first elicits the five areas of life considered most important by the individual in determining their QoL. The level of satisfaction /functioning in each area is next recorded followed by the JA task which allows the interviewer to determine the relative importance of each QoL area.

The psychometric data presented in this manual was derived from studies in which the SEIQoL was administered in exactly the manner described here. The following instructions should be adhered to as closely as possible, with additional instructions given ONLY if absolutely necessary, for example if the respondent does not understand the instructions as given.

In addition to this manual, you should have received the following templates:

- Cue Definitions Record Form
- Sample Cue Levels Record Form
- Cue Levels Record Form
- 30 Hypothetical Case Forms (20 + 10 replicates)
- Interview Record Form

You should make photocopies of these from the templates before commencing the interview. In addition you will need two pens or pencils.

2.2 Administration Procedure

Step 1: Introduction

Read the following to the respondent:

"For each of us, happiness and satisfaction in life depends on those parts or areas of life which are important to us. When these important areas are present or are going well, we are generally happy but when they are absent or are going badly we feel worried or unhappy. In other words, these important areas of life determine the quality of our lives. What is considered important varies from person to person. That which is most important to you may not be so important to me or to your husband/wife/children/parents/friends (mention one or two of these groups as appropriate)..**and vice versa".**

"I am interested in knowing what the most important areas of your life are at the moment. Most of us don't usually spend a lot of time thinking about these things. Indeed, we often only notice that certain things are important when something happens to change them.

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Sometimes it is easier to identify what is important by thinking about the areas of life that would (or do) cause us most concern when they are missing or are going badly."

Step 2: Eliciting the five most important aspects of life (Cues)

Ask the respondent:

"What are the five most important areas of your life at present - the things which make your life a relatively happy or sad one at the moment.....the things that you feel determine the quality of your life?"

If the respondent does not understand what is required the question may be re-phrased in the following ways :

"**What parts of your life are most important?../ What things are most important?../ 'The most important things in my life are...'."**

- elicit areas, NOT individuals, e.g. marriage, not wife. Do not give examples.

- The meaning of each cue for the respondent must be documented at this stage on the Cue Definitions Record Form. Establish what the respondent means by each quality of life area named as being important. For example, if an individual were to name 'golf' as a cue, this may relate primarily to leisure activity, but equally it may represent social activity, or physical mobility. Similarly, if 'religion' were named as a cue it might relate to the respondent's spiritual life, but might equally relate to being physically able to get to church, or to the social dimension of meeting one's friends at church. This is particularly important for subsequent review of data, and of obvious relevance when respondents must be re-assessed at some future date in order to ensure that the same cues are being considered.

- Having defined what the respondent means by the cue, it is important that the cue, as labelled by the individual, be used by the interviewer and not the interviewer's interpretation of what the respondent is saying.

- Should the respondent volunteer cues which resemble 'quality of life' in meaning (e.g. satisfaction, life quality), the interviewer should probe for more specific cues. Cues such as 'happiness', 'attitude to life', 'morale' are acceptable.

- If it is absolutely necessary to make some suggestions, then read the following list, excluding any cues already mentioned - **family, relationships, health, finances, living conditions, work, social life, leisure activities, religion/spiritual life.** This list is derived from our findings with a range of populations and represents the cues most commonly elicited, in descending order of frequency. It provides for consistency across interviewers where such prompting is absolutely necessary.

Step 3: Determining levels

Say to respondent:

"Now that you have named the five most important areas in your life, I am going to ask you to rate how each of these areas are for you at the moment. First I will show you an example of how the rating is done".

Place the Sample Cue Levels Record Form between you and the respondent so that the respondent can clearly see how you carry out the rating.

"First look at this box (indicate)**. As you can see, there are spaces at the bottom in which I can write five important life areas of my life** (indicate)**, and there is a scale along the left hand side** (indicate)**.**

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The scale ranges from 'worst possible' on the bottom to 'best possible' on the top, and passes through levels such as 'very bad' - 'bad' - 'neither good nor bad' - 'good' - and 'very good' between the two extremes.

The first important area of my life is X (use a cue not already nominated by the respondent and write it in the first space at the bottom of the rating box) **and if this is going very well at the moment, I can show this by drawing a bar like this** (draw a bar approx. 80mm high)**. I am using the scale** (indicate) **to decide how high my bar should be. The nearer I draw the bar to the bottom line, the poorer my rating of that area of my life and the nearer I draw it to the top line, the better my rating of that area of my life. A mark in the middle range would indicate that I am rating life as neither good nor bad, but somewhere in between."**

Now proceed with the ratings for the remaining cues :

Second cue - **"if X_2** (use a cue not already nominated by the respondent and write it in the second space) **is going as well as is possible, I would rate it by drawing a bar like this"...**(draw a bar 100mm high).

Third cue - **"if X_3** (use a cue not already nominated by the respondent and write it in the third space) **is going very badly, I would rate it like this"...**(draw a bar approx. 15mm high).

Fourth cue - **"if X_4** (use a cue not already nominated by the respondent and write it in the fourth space) **is just all right, or 'fifty/fifty', I would rate it like this"...**(draw a bar approximately 50mm high).

Fifth cue - **X_5** (use a cue not already nominated by the respondent and write it in the fifth space) **-** (draw a random rating).

"This provides a picture of life as I might think of it at the moment. Thinking of my life in this way, I can now make a decision about the overall quality of my life by marking on this line" (indicate the horizontal visual analogue scale (VAS) below the recording box).

"This line ranges from 'the worst life imaginable' on the extreme left to 'the best life imaginable' on the extreme right, passing through 'very bad' - 'bad' - 'neither good nor bad' - 'good' - and 'very good' between the two extremes.

If I make a mark in the middle of the line (indicate)**, it means that I am rating the quality of this life as "neither good nor bad". If I mark it towards the extreme left, like this** (indicate)**, it means that I am rating the quality of this life as the worst I can imagine. A mark towards the extreme right** (indicate) **would mean rating the quality of this life is the best I can imagine. In other words, the nearer I make my mark to the extreme left, the poorer my rating of that life, and the nearer I mark it to the extreme right, the better my rating of that life."**

You should demonstrate to the respondent by marking the VAS at a number of different points. Check with the respondent what he or she understands each mark to mean.

Step 4: Elicit rating of present life

Place the Cue Levels Record Form between you and the respondent. Write the respondent's five cues in the appropriate spaces under the box. Give the respondent a pen or pencil.

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Say to respondent:

"Now I want you to rate the five most important areas of your life, as you see presented here (indicate)**. Firstly, draw a bar which represents how you would rate yourself on each of these areas at the moment. As in the example I've just shown you, the nearer you draw the bar to the bottom line, the poorer you are rating that area of your life and the nearer you draw it to the top line, the better your rating of that area of your life".**

Have respondent draw bars.

"Now, thinking about these five areas of your life and how you have rated them, please indicate on this scale (indicate the horizontal visual analogue) **the point that best represents your overall quality of life at the moment".**

Have respondent complete rating.

Step 5: Judgment Analysis: rating hypothetical cases

Place the first of the hypothetical cases before the respondent. Rather than having to write the five cues under each of the 30 hypothetical cases, it is easier to write them, appropriately spaced, on a 'post-it' type sticker. This can be applied and re-applied under each box.

Say to respondent:

"So far we have talked about the way your life is at the moment. Now I would like you to look at a series of pictures, or profiles, that show how life could be for you. In each case I would like you to try to imagine what life would be like for you in such a situation. Then I want you to rate the overall quality of life that you would have, in such a situation, using the line underneath (indicate)**. Once again, this line runs from 'the worst life imaginable' to 'the best life imaginable' and you make your rating by placing a mark on the line to show how good or bad you feel such a life would be for you".**

Should the respondent find it impossible to imagine a particular scenario as being relevant to him or her, then you may orient him or her to the task by saying the following:

"Remember that even though these are imaginary profiles some of them may be situations that you could possibly find yourself in. Others may not be specifically relevant to you but other people can be faced with them from time to time. How would you rate your quality of life if you were in this situation?"

Have respondents complete ratings on all thirty hypothetical cases.

2.3 Potential problems in administration

The following are the problems most commonly encountered in SEIQoL administration.

- **Determining cue levels**

  The respondent conceives the task as drawing bars in terms of their importance rather than in terms of how these areas are for them at the moment.

  Suggested solution: Remind the respondent that the task is to "rate how each of these areas are for you at the moment".

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- **Using the Visual Analogue Scales**

- Respondent thinks that the task is to mark VAS underneath a particular cue (most important cue, least satisfactory cue, etc.).

- Respondent thinks that only a mark at either end of the VAS is allowed.

- Respondents thinks task is to make five separate judgments, one for each cue, on the VAS.

Suggested solution: In each of these instances the respondent has not understood the nature of the task. Explain again in detail (Step 3).

- Respondent confuses end-points of VAS and marks at end which seems inconsistent with verbal comments or earlier rating.

Suggested solution: Check with the respondent about the intention of the rating.

- **Conceptualising Judgment Analysis Task**

- Respondent compares cases with his or her own cue profile, and marks VAS according to 'goodness of fit'.

- Respondent thinks task is to judge how a case *should* look. For example if cue levels are all low then respondent may mark towards 'best life imaginable' commenting that this case should be better.

Suggested solution: In each of these instances the respondent has not understood the nature of the task. Explain again in detail (Step 5).

- Respondent views bar heights as representing importance rather than how these areas are for them at the moment.

Suggested solution: Remind respondent that bar heights represent how these areas are for them at the moment, and not their importance.

SECTION 3: SCORING THE SEIQoL

3.1 Recording Scores

Record on the Interview Record Form:

- the length of time the respondent took to complete the task
- the interviewer's rating of the respondent's understanding of the method
- whether the interviewer felt that the respondent became fatigued or bored during the task
- the interviewer's overall rating of the validity of the information obtained
- scores on the Visual Analogue Scales for the thirty hypothetical cases.

3.2 Multiple-regression Analysis:

Derivation of cue weights involves determining by means of multiple regression analysis the relative importance of each cue to the overall VAS judgment of QoL. Various statistical packages can handle this type of data. However, a specific programme Policy PC has been developed which makes the task somewhat easier. We have used this programme in al of our SEIQoL studies to date.

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The Policy PC Programme

Policy PC is an interactive computer programme using multiple regression analysis and specifically developed for analysing the results of judgment analysis techniques. A diskette and manual for this programme are available from Executive Decision Services, P.O. Box 9102, Albany, New York 12209, USA. The Policy PC manual explains data entry and analysis in a stepwise fashion; it is easy to use and is designed specifically for users with no previous computer experience. In addition to calculating cue weights, Policy PC also directly estimates internal validity ($R^{2)}$, a measure of the variance in QoL judgments explained by the five cues used (Section 5 - Validity).

3.3 Using the Policy PC Programme

The steps involved in extracting judgment policies are explained in detail in the Policy PC manual. Outlined below are the steps in the procedure required to use Policy PC specifically with the SEIQoL.

Setting up Policy PC for the SEIQoL

Having loaded Policy PC according to the Manual instructions the following steps should be followed; underlined phrases refer to programme instructions or questions:

1. Select New Block (option 1) from the initial menu and name the New Block.
2. Number of cases to be judged = 30.
3. Number of cues = 5.
4. Unless using provided cues (Section 5.2), name the cues 1, 2, 3, 4 and 5.
5. Do you wish the cue values to be text? - NO.
6. The minimum, maximum, step values for each cue are 1,10,1.
7. Number of judges = number of respondents: in most cases there will be a single respondent = 1.
8. Name of Judge 1 may be any name unlikely to be used again or the study number assigned to the respondent or the respondent's initials.
9. Judgment range is 0,100.
10. Select Old Block (option 2) from initial menu.
11. Type in name of block created in step 1.
12. Select Case Presentation (option 3) from initial menu.
13. Do you want to refine the cue set before judgments are entered? - NO.
14. Do you wish the judgments to come from an existing file? - NO.
15. Do you wish the cue values to be randomly generated? - NO.
16. Are cue values contained in an existing file? - NO.
17. Type name for new cue value set (e.g. SEIQoL30).
18. Cue values refer to the heights of the bars in the hypothetical cases and should be entered as follows.

CASE 1	1,10,2,9,9	CASE 11	7,5,7,6,10	CASE 21	10,5,10,4,9
CASE 2	9,8,4,8,5	CASE 12	6,9,1,5,5	CASE 22	7,5,3,8,9
CASE 3	3,1,1,10,8	CASE 13	10,2,9,8,1	CASE 23	8,7,2,6,1
CASE 4	4,3,9,3,6	CASE 14	10,1,1,5,6	CASE 24	7,9,5,8,7
CASE 5	4,10,6,3,8	CASE 15	7,9,5,8,7	CASE 25	10,2,9,8,1
CASE 6	1,5,3,3,1	CASE 16	9,6,5,10,8	CASE 26	4,10,6,3,8
CASE 7	9,7,4,1,5	CASE 17	9,2,10,10,8	CASE 27	7,5,7,6,10
CASE 8	9,4,4,9,10	CASE 18	6,2,10,9,2	CASE 28	6,2,10,9,2
CASE 9	9,8,4,8,5	CASE 19	6,1,7,6,5	CASE 29	3,1,1,10,8
CASE 10	7,5,3,8,9	CASE 20	1,5,3,3,1	CASE 30	4,3,9,3,6

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3.4 Deriving SEIQoL outcome data

The problem of missing data should not arise when using the SEIQoL because the method is administered by interview. However, in the event of it being a problem, for example if the interviewer inadvertently skips a case, or a case has been omitted from the hypothetical cases, then it is suggested that set of judgments be analysed separately, entering twenty-nine cases to the Policy PC program rather than thirty. Any further missing data is likely to decrease significantly the variance explained. The SEIQoL yields the following outcome data :

(i) Cue labels and their definitions
(ii) Cue levels
(iii) Cue weights
(iv) Internal validity
(v) Internal reliability
(vi) The SEIQoL index

(i) Cue Labels and their Definitions

During Step 2 (eliciting the five most important aspects of life), the meaning of each cue for the respondent is summarised on the Cue Definitions Record Form, together with the label that the respondent used for each cue. For example, different respondents may use "religion" as a cue label, but it can have various meanings: a spiritual activity; a social activity (meeting friends at services) or a physical activity reflecting mobility (being able to walk to services). The definition is important for subsequent understanding of what was meant by the cue label. It is also important in summarising cues from a number of respondents for grouped data presentation.

(ii) Cue Levels

The cue levels are elicited during Step 3 when the respondent draws five bars on the Cue Levels Record Form. Levels are scored by measuring the vertical height of each bar in millimetres. This yields five scores which are independent continuous measurements, ranging from 0 to 100. They can be analysed using parametric statistical methods.

(iii) Cue Weights

The cue weights are derived by entering into the Policy PC programme the respondent's global QoL ratings on the visual analogue scales for the thirty hypothetical cases presented during Step 5 (Judgment Analysis). For each hypothetical case use a ruler to measure the respondent's QoL rating on the horizontal visual analogue line. Measure in millimetres from the left-hand side and record each score on the Interview Record Form. Refer to the Policy PC reference manual for use of this system. The weights always sum to 1.0 and are therefore not independent for the purpose of statistical analysis.

Entering data to Policy PC for individual respondents.

1. Repeat steps 10-15 in Section 3.3 above.
2. Are cue values contained in an existing file? - YES.
3. Type name of cue value set created in Step 17 above.
4. Enter visual analogue scores for the 30 cases and save.
5. Select Extract (option 4) from initial menu to calculate weights.
6. Do you wish all function forms to be estimated quadratically? - YES.
7. Do you wish the quadratic term calculated by subtracting the cue mean? - YES.
8. No. of policies = 1
9. Judge number = 1.
10. Do you wish the analysis to be run automatically? = NO
11. Do you wish statistics displayed? = YES.
12. Press return three times and note the first R^2 (internal validity) estimate from the bottom of the screen.
13. Press return four times and note the first cue weight.
14. Press return for each of the subsequent cue weights.

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(iv) Internal Validity

As previously described, Policy PC computes R^2, a measure of the variance in QoL judgments explained by the five cues used. This statistic provides an estimate of the internal validity of judgment analysis. Caution should be exercised in interpreting judgment policies in which R^2 is less than 0.7.

(v) Internal Reliability

The Policy PC programme does not calculate internal reliability and the administrator must do this by calculating a Pearson correlation on the VAS scores for the 10 replicate cases. Calculate the Pearson correlation on the global visual analogue scores for repeated cases as follows:

CASE 2 - CASE 9	CASE 10 - CASE 22
CASE 3 - CASE 29	CASE 11 - CASE 27
CASE 4 - CASE 30	CASE 13 - CASE 25
CASE 5 - CASE 26	CASE 15 - CASE 24
CASE 6 - CASE 20	CASE 18 - CASE 28

(vi) The SEIQoL Index

The SEIQoL is intended primarily as an individual measure. Where group comparisons are required, a global index can be calculated which may be used in within-subject or between-subject study designs. As the index is a continuous measure ranging from 0 to 100 it can be analysed using parametric statistical methods. Having obtained levels and weights for each of the five cues, as described previously, the SEIQoL index is calculated as follows:

- For each cue multiply the level by the weight, then sum these products across the five cues: **SEIQoL Index =∑(levels x weights)**

Care should always be taken in interpreting the index, as it is the sum of the products of individual cue levels by cue weights, each of which may vary independently. The index should be interpreted in the context of the pattern of levels and weights generated for each respondent.

3.5 Presenting Data

The data from each individual respondent can be presented in tabular form giving the elicited cues, the levels, the weights and internal reliability (r) and internal validity (R^2). For grouping data SEIQoL Index scores may be presented (cf. McGee et al., 1991, O'Boyle et al., 1992).

SECTION 4: RELIABILITY OF THE SEIQoL

4.1 Cue Elicitation

Individually defined QoL can change in a number of ways. The areas which are considered important by the individual may change, their levels may change and/or the relative importance of cues to each other may change. The stability of elicited cues over time was examined by calculating the mean number of cue changes for the samples in whom no intervention occurred between interviews. The important question is whether individuals nominate the same cues after an elapsed period of time.

For a healthy adult sample (Study 6.4: control group), the mean number of cue changes was 1.1 (sd: 0.94; range = 0-3) over 7.5 months and 1.3 (sd: 0.83; range = 0-3) over 24 months. For a healthy elderly sample (Study 6.3) the mean number of cue changes was 1.1 (sd: 0.76; range = 0-3) over 12 months.

These results indicate that the domains which individuals judge to be important to their QoL are likely to remain relatively constant over periods as long as two years.

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However, they may change and, consequently, if the SEIQoL is being used in a repeated measures design it will be necessary to decide in advance whether to elicit cues again on repeated testing or to require respondents to rate the previously elicited cues. We suggest that both should be done. The full SEIQoL should be administered at the repeat testing and if new cues are found these should be rated. Following this, the JA task can be re-presented using cues from the first test time.

As the cues elicited are easily remembered over a short period of time, measures of inter-rater agreement by serial elicitation of cues is precluded. At present, no research has been completed on inter-rater reliability for cue elicitation. Test-retest reliability of cue elicitation over short periods is also precluded by recall effects.

4.2 Cue Levels

(i) Test-retest Reliability: before and after JA

In study 6.3, elderly respondents were required to rate their cue levels before and after JA, in order to assess the reliability of these ratings. This procedure was carried out at baseline and 12 months later. Correlations between levels at different times cannot be calculated due to the small number of levels (five) to be correlated. The mean absolute difference between cue levels before and after JA was calculated for each respondent and then averaged across respondents to give the mean distance between ratings for a sample. At baseline, the average mean difference between cue levels before and after JA was 7.0 (sd: 5.2; range = 0-21). At 12 months the average mean difference was 10.7 (sd: 6.2; range = 0-24.2).

(ii) Stability over longer periods

In study 6.4, a control sample of healthy adults received no intervention and cue levels for the same cues were measured at baseline, 7.5 months and 24 months. The average mean difference in cue levels was 12.9 (sd: 6.3; range = 4-26) from baseline to 7.5 months and 12.2 (sd: 4.8; range = 5-22) from baseline to 24 months.

4.3 Judgment Analysis of Weights

(i) Internal reliability

Table 1. *Internal reliability of judgment analysis in studies to date*

Study No.	Sample	Mean r
6.1	Healthy adults (n=42)	0.74
6.2	Healthy adults (n=40)	0.73 (baseline) 0.75 (7-10 days)
6.3	Healthy elderly community residents (n=56)	0.66 (baseline) 0.73 (12 months)
6.4	Osteoarthritis patients undergoing total hip replacement (n=20)	0.64 (pre-op) 0.49 (7.5 months) 0.62 (24 months)
	Healthy matched adult controls (n=20) for the hip replacement sample	0.71 (baseline) 0.62 (7.5 months) 0.66 (24 months)
6.5	Irritable Bowel Syndrome patients (n=28) Peptic Ulcer Disease patients (n=28)	0.62 0.70

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Standard 30-case Judgment Analysis contains ten repeat cases which allow calculation of the internal reliability of the procedure. Mean Pearson's r correlations for these ten repeat cases are presented in table 1 for the various samples studied to date.

(ii) Test-retest Reliability of JA weights

In study 6.2 a sample of healthy adults provided weights for the same cues at baseline and 7-10 days later. The average mean change in JA weights over this period was 8.44 (sd: 3.8; range = 1.6-16.8).

(iii) Stability of JA weights over time

In study 6.4, a sample of healthy adults received no intervention and provided weights for the same cues at baseline, 7.5 months and 24 months later. Because the Policy PC programme constrains the weights to sum to a total of 1.0, the relative weights cannot be considered as independent observations for the purposes of statistical analysis. Thus the same procedure used to estimate the stability of cue levels was performed. Average mean difference in weights was 10.3 (sd: 5.2; range: 3.6-22.8) from baseline to 7.5 months and 8.0 (sd: 4.0; range: 3.0-16.8) from baseline to 24 months.

4.4. The SEIQoL Index

The SEIQoL is designed to measure QoL at a particular point in time and should therefore be responsive to change. One would expect that QoL is a state type construct which should vary over time. Changes were examined by correlating SEIQoL Index scores recorded over time in populations receiving no intervention. For a healthy adult population (study 6.4), Pearson's r = 0.33 between scores at baseline and at 7.5 months later. For the same population, Pearson's r = 0.18 between QoL scores at baseline and QoL scores 24 months later. For a healthy aged population, (study 6.3) Pearson's r = 0.45 between QoL scores at baseline and 12 months later. These findings indicate that the scores do fluctuate with time in normal healthy populations as would be expected.

SECTION 5: VALIDITY OF THE SEIQoL

The key concern in assessing the validity of a measure is whether it measures what it purports to measure - in this case individual QoL. According to Anastasi (1988 p.164) the 'validation process begins with the formulation of detailed trait or construct definitions, derived from psychological theory, prior research or systematic observation and analysis of the relevant behaviour domain' We have outlined the assumptions underlying our definition of QoL in section 1.3 above.

5.1 Content Validity

Does the SEIQoL include a representative sample of the behaviour domain under measurement and exclude irrelevant factors? The structure of the SEIQoL is such that individuals themselves generate the sample of items (cues) for inclusion in the QoL assessment.

The number of cues to be elicited was set at five for a number of reasons. Firstly, research indicates that most individuals experience difficulty in making judgments requiring the combination of information from a large number of cues and studies of decision making have made use of relatively few cues (Stewart, 1988b). The number of cases which the individual must judge increases in direct proportion to the number of cues on which the judgments must be made. Ten cases are required for three cues and a further 5 cases for each additional cue (Policy PC Manual) thus giving a requirement of 20 cases for 5 cues. In the SEIQoL, 10 replicates are also included to calculate internal reliability. This gives a total requirement of 30 cases.

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A variety of cues has been elicited in SEIQoL studies to date. Table 2 outlines the general nature of cues obtained from a sample of healthy young adults (study 6.1) and a sample of the healthy elderly subjects (study 6.3). The particular cues elicited from participants have been arranged in broad categories for the purposes of summarising results. However, the actual cues and range of combinations of cues are many. For example, only two of forty-two healthy adults in study 6.1 named five similar cues.

Table 2. *Percentage of healthy elderly and healthy young adults nominating particular cues as relevant to their quality of life.*

	% Healthy Elderly (n=56)		% Healthy young adults (n=42)
Cue Category	Baseline	12 months	
Family	89	89	62**
Social and leisure activities	95	59	38*
Health	91	87	83
Living conditions	80	89	21**
Religion	75	84	7**
Independence	16	14	19
Finances	25	43	60*
Relationships	18	21	86**
Work	5	7	38**
Happiness	5	5	48**

* $p < 0.05$ for chi-square comparisons between healthy young adults and the elderly sample at baseline.

** $p < 0.05$ for chi-square comparisons indicating differences between the young adults and the elderly at both baseline and also at 12 months.

Internal Validity

The extent to which judgment policies derived from JA explain the overall judgments of QoL made by the individual may be assessed from the variance (R^2) estimate provided by Policy PC. Higher variance scores indicate that the combination of cues elicited is in fact that used by the individual in making overall QoL judgments. All but one of the study samples have provided acceptable mean internal validity scores exceeding 0.70 (Table 3). In the case of patients with osteoarthritis, R^2 was somewhat lower.

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Table 3. *Internal validity (R^2) of judgment analysis in SEIQoL studies to date.*

Study No.	Sample	Mean R^2
6.1	Healthy adults (n=42)	0.75
6.2	Healthy adults (n=40)	0.78 (baseline) 0.79 (7-10 days)
6.3	Healthy elderly community residents (n=56)	0.72 (baseline) 0.78 (12 months)
6.4	Osteoarthritis patients undergoing total hip replacement (n=20)	0.62 (pre-op) 0.65 (7.5 months) 0.64 (24 months)
	Healthy matched adult controls (n=20) for the hip replacement sample	0.76 (baseline) 0.72 (7.5 months) 0.71 (24 months)
6.5	Irritable Bowel Syndrome patients (n=28)	0.73
	Peptic Ulcer Disease patients (n=28)	0.79

5.2 Construct Validity

Does the measure assess the theoretical construct of individual QoL? Two fundamental aspects of the measure; individual cue generation and individual weighting of cues can be assessed.

(i) Evidence of need for an individual approach: cues

Most traditional measures purporting to measure QoL provide the individual with a pre-determined list of items which are previously weighted on the basis of grouped data. Our studies show that, while a number of cues frequently assessed by such instruments were often elicited using the SEIQoL (e.g. health, family and work), other cues such as religion, finance and education were also nominated. Cues unique to a single study participant (e.g. politics, aesthetics) were also elicited regularly.

Can cues be provided?

In a number of studies we have provided participants with cues derived from more traditional health status questionnaires. QoL assessment using these cues was possible and provided acceptable internal validity scores, e.g. $R^2 = 0.79$ in a sample of healthy adults (Study 6.1) and $R^2 = 0.74$ in a sample of patients undergoing hip replacement (Study 6.1). However, the correlation between elicited cues QoL and provided cues QoL was moderate (Pearson $r = 0.49$) for the healthy adult sample. SEIQoL index scores based on provided cues were not sensitive to surgical intervention. Scores did not show significant improvement following total hip replacement (change from 66.1 to 70.6 over 7.5 months; n.s.) while SEIQoL index scores derived using an elicited cues format were sensitive to the surgery (change from 61.6 to 70.7 over 7.5 months; $p<0.02$).

Does age have an effect?

Different cues might be expected to be important to individuals at different stages in the life-cycle. A comparison of a healthy younger and older adults (Studies 6.1 and 6.3, respectively) showed that areas such as religion and social and leisure activities were nominated significantly more often by the older group (Table 2). Areas such as work and relationships (as distinct from family) were more often identified by the younger group.

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These differences are what might be expected in Western society and are consistent with theoretical models of the life-cycle such as that proposed by Erikson (1963).

SEIQoL in health and disease.

QoL as defined by SEIQoL is not equivalent to health status. Health was not the most commonly nominated cue in most studies to date, including studies where the sample was defined on the basis of health problems and interviewed in a medical context (e.g. hip replacement, irritable bowel syndrome, peptic ulcer disease).

In patients with severe osteoarthritis, (Study 6.4) for example, health was not nominated as an important cue by all participants. In fact, only 10/20 patients and 14/20 controls respectively, mentioned health. Patients with osteoarthritis accorded lower weights on average to the provided cue 'general health' than did controls (Table 6).

(ii) Evidence of need for individual approach: weights

Weights may change over time. For example, patients who had received a hip replacement 7.5 months previously gave significantly greater weighting to the 'general health' cue post-operatively while controls did not change their weighting as a group (table 6). Average weights for the provided cue 'physical functioning', 'emotional functioning', 'social functioning' and 'living conditions' did not change with time.

Table 4. *Average weights assigned by patients and controls to the provided cue 'General health'.*

	Baseline	**7.5 months post-op**	
	Mean (sd)	Mean (sd)	
Hip replacement patients	0.28 (0.10)	0.35 (0.13)	($p < 0.01$)
Controls	0.33 (0.13)	0.35 (0.14)	(ns)

Respondents are also able to recognise weighting policies that have been captured through JA, establishing the criterion validity of the procedure. In study 6.2 a sample of healthy adults provided a weighting policy (5 weights summing to 1.0) for five elicited cues via JA. 7-10 days later they were presented with 10 weighting policies for the five elicited cues, and asked to rank order them in terms of how well they fitted their own current policy for those cues. Unknown to the subjects, one of the weighting policies was the JA policy they had previously provided. The mean rank given to their own policy was 2.87, with 62.5% of subjects placing their policy within the first three ranks, and all subjects placing it within the first five.

In patients with gastrointestinal disorders (Study 6.5), the SEIQoL index was more sensitive to differences between the groups than a summary score based on mean cue levels alone. When patients with irritable bowel syndrome (IBS) were compared with those who had peptic ulcer disease (PUD) the differences between the groups were just significant for scores based on mean levels alone. However, Index scores incorporating weights clearly discriminated between the groups. Incorporating weights dramatically changed individual scores. Paired t-tests between SEIQoL index scores and scores based solely on mean cue levels showed highly significant differences for the two groups ($p<.001$ for PUD and $p<.0004$ for IBS).

5.3 Relationship with other Measures

QoL, as measured by SEIQoL, is related to health measures in the expected direction but is not sufficiently similar to any measure yet assessed to negate its unique contribution to the measurement of QoL.

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(i) Hip Replacement Study (6.4)

This study compared global SEIQoL scores with those derived from a general measure of health status: the McMaster Health Index Questionnaire (MHIQ; Chambers et al., 1982). The MHIQ is derived from the World Health Organisation definition of health as comprising physical, social and emotional well-being. The questionnaire comprises three subscales corresponding to these 3 components of well-being. The correlation between SEIQoL index scores and total MHIQ scores was r = 0.21. Both measures were sensitive to hip replacement surgery but the sensitivity of the MHIQ reflected changes only on the physical functioning subscale.

The SEIQoL was also compared with the Arthritis Impact Measurement Scales (AIMS; Meenan et al., 1980) a disease-specific measure of QoL for arthritis. SEIQoL index scores correlated only moderately ($r = -0.25$; $p < 0.05$) with those of the AIMS.

The mean correlation between the SEIQoL index scores and the Harris Hip Rating, a physical functioning scale (Harris, 1969) was r = 0.12. This indicates that the SEIQoL is measuring something other than physical functioning.

SECTION 6: STUDIES USING THE SEIQoL

6.1 Individually Defined Quality of Life in a Healthy Adult Sample.

FOCUS: Initial psychometric evaluation of the SEIQoL methodology.
STRUCTURE: Sample of healthy adults.
TIME FRAME: Single interview.
SAMPLE SELECTION: Consecutive attendees at the International Immunisation Clinic of the Royal College of Surgeons in Ireland for inoculation/vaccination before travel abroad. The sample comprised 42 individuals (20m/ 22f). Mean age was 28.8 (range = 19-51). All participants could complete the SEIQoL.

SEIQoL CUE PARAMETERS:

(a) elicited cues.
(b) provided cues: 5 cues provided from general QoL research (physical, social and emotional functioning, living conditions and general health) presented after the elicited cue task.

STUDY RESULTS:

Features of life elicited as important to QoL by individuals are outlined in table 2. Some cues such as family were common to many individuals. However, some cues such as religion or education were nominated by only a few individuals. Not all subjects mentioned health as an important aspect of their QoL. Of the 35 who did, there was considerable variability in the weight attached to it. JA weights for health ranged from 0.03 to 0.59 of a maximum possible 1.0. This illustrates the variability in individual definitions of QoL.

Table 5. *Study results of young healthy adult study.*

	Elicited cues			**Provided cues**		
	Mean	sd	Range	Mean	sd	Range
SEIQoL index	77.4	9.5	52.0-95.3	80.0	7.0	61.5-96.0
Internal reliability	0.74	0.07	0.15-0.95	0.69	0.18	0.13-0.95
Internal validity	0.75	0.13	0.46-0.94	0.79	0.11	0.47-0.93

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Table 6. *Range of weights attributed to five provided cues in judgment decisions on QoL using the SEIQoL.*

	Mean weight	Range
Physical functioning	0.22	0.03-0.38
Social functioning	0.14	0.05-0.44
Emotional functioning	0.24	0.02-0.46
Living conditions	0.14	0.02-0.30
General health	0.26	0.09-0.54

The relationship between SEIQoL Index scores based on elicited and provided cues was significant (Pearson $r = 0.49$, $p < 0.001$) but accounted for less than 25% of the common variance. Thus, the measures are not interchangeable. The mean index scores from the two measures do not differ significantly (Table 5).

Examination of cue weights in the provided cue version of the SEIQoL (table 6) illustrates the variability in cue weights which occur in a healthy sample. The SEIQoL is one of the few QoL measures which measures the weight attached to a particular aspect of Qol by respondents.

This initial study illustrated the individual and phenomenological nature of QoL. Different cues were nominated and the relative importance of the same cues also varied from person to person. The ability of all participants to complete the SEIQoL and the resultant levels of internal reliability and validity which were high, justified further exploration of the measure with patient populations.

6.2 Psychometric Properties of Judgment Analysis in a Healthy Adult Sample.

FOCUS: Test-retest reliability and criterion validity of judgment analysis.
STRUCTURE: Repeated measures study in a sample of healthy adults.
TIME FRAME: Interviews at baseline, 7-10 days and 14-20 days.
SAMPLE SELECTION: Staff members of a medical college and postgraduate research students of a psychology department. The sample comprised 40 individuals (15m/ 25f). Mean age = 31.2 (range = 20-53). All could complete Judgment Analysis.

SEIQoL CUE PARAMETERS: elicited cues.

PROCEDURE: At baseline (t1) five cues were elicited. Judgment analysis was carried out using these cues at baseline and 7-10 days (t2) in order to establish test-retest reliability. A further 7 to 10 days later (t3) subjects received a questionnaire by post containing ten weighting policies for the five cues. A policy refers to five weights that sum to 1.0. Of these ten policies, one was the JA policy provided by the subject concerned at t2. Unaware of this, subjects were requested to rank order the policies in terms of how closely they resembled their own current policy for the cues. These ranks were then used as a measure of criterion validity. The aim was to determine whether subjects could select from a range of alternatives their particular judgment policy (Reilly and Doherty, 1989).

STUDY RESULTS:

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Table 7. *Internal reliability and validity of JA at time 1 and time 2.*

	Time 1			Time 2		
	Mean	sd	range	Mean	sd	range
Internal reliability	0.73	0.2	0.29-0.90	0.75	0.2	0.35-0.93
Internal validity	0.78	0.1	0.58-0.93	0.79	0.1	0.37-0.94

The average mean difference between JA weights at t1 and t2 was 8.44 (sd: 3.8; range = 1.6-16.8).

Recognition of JA Policies.

Seven subjects (17.5%) gave their first rank to the JA policy most closely resembling their current policy, 10 (25%) ranked the appropriate JA policy second, 12 (30%) ranked it third, 3 (7.5%) ranked it fourth and 8 (20%) ranked it fifth. The mean rank for JA policies was 2.87 (range 1-5) from a possible 10. Therefore, 62.5 % of respondents placed their own judgment policy within the first three ranks and all subjects placed it within the first five.

These findings indicate that, in general, policies derived from JA closely resembled those which subjects felt were their own policies.

6.3 Individual Quality of Life in the Healthy Elderly.

FOCUS: Normative study of quality of life in the healthy elderly.
STRUCTURE: Longitudinal study of a cohort of healthy elderly.
TIME FRAME: Sample interviewed at baseline and 12 months later.
SAMPLE SELECTION: Randomly selected general practitioners in urban Dublin area were contacted and asked to participate in study. Sixty seven healthy respondents were randomly selected from general practitioner files, and were interviewed at baseline. Health criteria were: (a) not on prescribed medication, (b) not on a waiting list for medical treatment, (c) no chronic disorder, (d) no acute disorder requiring prescribed medication within previous six months. Seven (9.6%) were unable to understand the SEIQoL. Of the 60 respondents who had completed the SEIQoL at baseline, 2 had died and 2 were incapacitated by ill-health at 12 months. Thus, the study sample comprised 56 healthy aged community residents (22m/ 34f) of mean age = 73.7 years (range - 65-90).

SEIQoL CUE PARAMETERS: General life area cues elicited at time 1 and time 2.

OTHER MEASURES: Other measures used were: (a) Self Evaluation of Life Functioning scale (SELF) , adapted to measure physical, social and psychological functioning in aged samples (Linn and Linn, 1985); (b) Mini- Mental State Examination, a brief measure of cognitive impairment (Folstein et al., 1975); (c) Life Satisfaction Index, a measure of successful ageing (Neugarten et al., 1961); (d) Life Experiences Survey, a measure of the number and perceived impact of life changes occurring in the previous 12 months (Sarason et al., 1978).

STUDY RESULTS:

SEIQoL Index scores and psychometric indicators derived from SEIQoL are shown in table 12. SEIQoL Index scores were correlated with psychosocial measures at baseline and 12 months as shown in Table 9.

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Table 8. *Mean, SD and range of overall QoL scores, internal reliability and internal validity co-efficients for a healthy elderly cohort.*

	Baseline			12 months		
	Mean	sd	range	Mean	sd	range
SEIQoL index	82.1	12.2	47.3-100	80.06	11.2	51.9-100
Internal reliability	0.66	0.24	0.01-0.94	0.73	0.18	0.36-0.98
Internal validity	0.72	0.15	0.30-0.92	0.78	0.12	0.41-0.97

Table 9.*Pearson r correlations between SEIQoL Index scores and a range of psychosocial measures at baseline and at 12 months for a healthy elderly cohort.*

MEASURE	Correlation with SEIQoL Index	
	Baseline	12 months
Self Evaluation of Life Functioning		
Symptoms of ageing	-0.07	-0.43*
Self-esteem	-0.15	0.03
Social satisfaction	-0.22	0.03
Depression	-0.13	-0.27
Personal control	0.12	-0.34*
Mini-Mental State Examination	0.13	-0.24
Life Experiences Survey		
Number of life events	0.10	0.08
Mean overall impact of life events	0.06	0.005
Life Satisfaction Index	0.17	0.29

* $p < 0.01$

6.4 Individual Quality of Life in Patients undergoing Total Hip Replacement Surgery.

FOCUS: Prospective longitudinal study to determine the sensitivity of the SEIQoL to change following a surgical intervention. Comparison of SEIQoL using cues elicited from the respondents with SEIQoL in which cues were provided by the investigator. Comparison of the SEIQoL with disease-specific health-status measures.

STRUCTURE: Patients undergoing total hip replacement (THR) surgery compared with matched community controls.

TIME FRAME: 6 weeks before, 7.5 months after and 2 years after THR surgery for patients and equivalent time for controls.

SAMPLE SELECTION: Consecutive patients with unilateral osteoarthritis of the hip and scheduled for THR at one centre were interviewed to achieve a sample of 20 (7m/13f). Mean age of the patient sample was 65.2 (range = 45-80). Controls were healthy adults selected from one general practice register and matched with patients by age, sex and social class. Mean age of the control sample was 63.4 (range = 43-78).

SEIQoL CUE PARAMETERS:

a) Elicited cues: Patients were asked to nominate their 5 most important cues pre-operatively. Following surgery the SEIQoL was administered using these previously nominated cues. In addition, cues were again elicited in order to determine the proportion of patients in whom the nominated cues changed.

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(b) 'Provided' cues: 5 general cues (i.e. physical, social and emotional functioning, living conditions and general health) reflecting areas normally included in health status measures were provided and the SEIQoL completed using these cues.

STUDY RESULTS:

Table 10a: *Study results for elicited cues.*

	THR patients			Controls		
	Mean	SD	Range	Mean	SD	Range
Baseline						
SEIQoL Index	61.6	18.8	27.4-96.0	60.7	9.4	37.2-73.2
Internal reliability	0.64	0.30	0.08-0.95	0.71	0.24	0.10-0.96
Internal validity	0.62	0.19	0.25-0.97	0.76	0.14	0.25-0.94
7.5 months post-operative						
SEIQoL Index	70.7	11.2	50.0-86.7	59.8	15.6	24.8-83.3
Internal reliability	0.49	0.22	0.01-0.96	0.62	0.34	0.03-0.96
Internal validity	0.65	0.16	0.33-0.94	0.72	0.13	0.42-0.88
24 months post-operative						
SEIQoL Index	69.3	10.2	39.9-91.3	61.3	9.0	44.7-73.3
Internal reliability	0.62	0.26	0.02-0.86	0.66	0.27	0.15-0.96
Internal validity	0.64	0.17	0.39-0.88	0.71	0.23	0.40-0.91

Using elicited cues, the SEIQoL was sensitive to changes in quality of life following hip replacement surgery. SEIQoL Index scores were positively, although not strongly, correlated with those of the McMaster Health Index questionnaire and the Arthritis Impact Measurement Scales (cf. Section 5.3 of this manual). SEIQoL Index scores derived from cues provided by the investigator were insensitive to the change in quality of life following surgery.

Table 10b. *Study results for provided cues.*

	THR patients			Controls		
	Mean	SD	Range	Mean	SD	Range
Baseline						
SEIQoL Index	66.1	12.5	41.0-87.4	65.6	14.3	28.9-83.4
Internal reliability	0.68	0.22	0.12-0.90	0.64	0.28	0.04-0.94
Internal validity	0.74	0.14	0.43-0.90	0.72	0.14	0.31-0.91
7.5 months post-operative						
SEIQoL Index	70.6	8.5	55.6-88.4	65.9	13.9	28.3-90.2
Internal reliability	0.46	0.29	0.04-0.97	0.73	0.14	0.47-0.95
Internal validity	0.76	0.13	0.46-0.93	0.82	0.19	0.65-0.93
24 months post-opeative						
SEIQoL Index	70.7	12.2	43.3-98.0	65.0	11.2	33.1-78.4
Internal reliability	0.58	0.26	0.05-0.90	0.56	0.26	0.02-0.89
Internal validity	0.66	0.15	0.28-0.91	0.71	0.15	0.26-0.91

The data from this study support the validity of the SEIQoL since the measure is sensitive to change, is related, but not strongly, to measures of functional status, and is more sensitive to change if the patients' own cues are used.

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6.5 Individual Quality of Life in a Gastroentorology Unit Sample.

FOCUS: Description of quality of life for two distinct patient groups and comparison of SEIQoL results with those of health and functional status measures.

STRUCTURE: Patients attending an out-patient clinic for treatment of irritable bowel syndrome (IBS) or peptic ulcer disease (PUD).

TIME FRAME: Cross-sectional single interview.

SAMPLE SELECTION: 28 patients (12m/ 16f) with irritable bowel syndrome (IBS) and 28 patients (16m/ 12f) with peptic ulcer disease (PUD). Patients were consecutive out-patient attendees at a gastroenterology unit. Mean age of the IBS sample was 33.2 (range = 17-64) and mean age of the PUD sample was 35.9 (range = 19-72). All patients were able to complete the SEIQoL.

SEIQoL CUE PARAMETERS: elicited cues.

OTHER MEASURES: The Gastrointestinal Symptom Rating Scale (GSRS) (Svedlund et al, 1988), a 15-item symptom scale designed for use with IBS and PUD populations, was completed by the attending physician. Illness-related QoL was assessed using the Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis, 1986), a self-report measure designed to measure patient adjustment to illness on seven domains: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment and psychological distress. Health status was assessed by means of the Nottingham Health Profile (NHP) (Hunt et al, 1986). This measure comprises two parts. Part I consists of statements describing health problems in six domains: energy, pain, emotional reactions, sleep, social isolation and mobility. Part 2 lists 7 likely problem areas (job, household management, social life, family life, sex life, interests and hobbies and holidays). Respondents indicate if their present state of health is causing problems with any of these areas.

STUDY RESULTS:

Table 11. *Mean, SD and range of overall QoL scores, internal reliability and internal validity co-efficients for IBS and PUD samples.*

	IBS			**PUD**		
	Mean	sd	range	Mean	sd	range
SEIQoL Index	62.9	17.4	25.8-95.4	72.6	12.6	50.9-93.8
Internal reliability	0.62	0.33	-0.69-0.95	0.70	0.26	-0.21-0.96
Internal validity	0.73	0.15	0.23-0.90	0.79	0.10	0.54-0.92

The dimensions of life considered important for QoL and the frequency with which they are mentioned by both groups are illustrated in table 11. Health was nominated less frequently by the PUD group than by the IBS group or healthy sample. This finding indicates that the presumption that health is automatically an important component of patients' perceived quality of life may not be warranted. Health may be viewed by patients as facilitating other important aspects of their lives rather than something to be valued in isolation.

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Table 12. *Elicited cues for the PUD and IBS groups and for the healthy young adult group (Study 6.1). Data show the percentage of respondents who nominated each cue.*

Cue Category	% Healthy	% IBS	% PUD
Relationships	86	36*‡	50‡
Health	83	89*	61‡
Family	62	100*‡	93‡
Finance	60	57*	39‡
Happiness	48	14‡	7‡
Work	38	61‡	57‡
Social and Leisure	38	82‡	75‡
Living conditions	21	29*	50‡
Education	19	4‡	11
Independence	19	4‡	11
Religion	7	7	14
Misc.	17	18*	32‡

* Significantly (at least $p<0.05$ for chi-square test) from PUD group.
‡ Significantly (at least $p<0.05$ for chi-square test) from healthy group.

The GSRS scale indicated that patients with IBS suffered higher levels of symptomatology than did the PUD group (Table 12). SEIQoL Index scores but not PAIS or NHP scores significantly distinguished the two groups, indicating that IBS patients as a group had significantly lower QoL than the PUD patients. The mean QoL of the IBS group, but not the PUD group, was also significantly lower than that of the young healthy sample (mean 77.4; sd: 9.5; $t = -3.3$, $p < 0.01$; Study 6.1). This finding is supported by research and by clinical perceptions that IBS disrupts QoL to a greater degree than does PUD (e.g. Whitehead et al, 1982; Guthrie et al, 1987).

Table 13. *Mean symptom ratings (sd.), SEIQoL Index scores and summary scores on the NHP and PAIS for PUD and IBS groups.*

Measure	IBS	PUD
Gastrointestinal Symptom Rating Scale	17.7 (5.3)	14.1 (6.5) *
SEIQoL Index	62.9 (17.4)	72.6 (12.6) **
PAIS Total Score	37.9 (14.0)	32.3 (16.2)
NHP Part 2 Total score	2.3 (1.8)	1.9 (2.0)

* $p < 0.05$; ** $p < 0.01$ for comparisons between groups.

Although IBS patients were ambulatory, living in the community and continuing with activities of daily living such as employment, they were more likely to perceive that their QoL was impaired by their condition. On the health status measures IBS patients scored significantly lower than PUD patients only on the psychological distress scale of the PAIS and on the social isolation scale of the NHP.

Relationships among measures

There were no significant relationships between the SEIQoL Index scores and either PAIS subscale or total scores. Neither was there a relationship between SEIQoL Index scores and scores on Part 2 of the NHP. SEIQoL scores were significantly related to 2 of 6 subscales of Part 1 of the NHP: sleep ($r = 0.38$, $p < 0.01$) and social isolation ($r = -0.29$, $p < 0.05$). Total scores on the PAIS and the NHP (Part 2) were significantly related ($r = 0.69$, $p < 0.001$). SEIQoL scores did not correlate with the medical severity rating on the GSRS. The GSRS was not significantly correlated with the PAIS total score but showed a modest relationship with the NHP (part 2) summary score ($r = 0.33$, $p < 0.05$). Low correlations between medically-rated symptomatology on the GSRS and patient-rated measures of QoL indicated that quality of life was not directly proportional to severity of medical symptoms in this sample. The results suggest that clinical assumptions about patient QoL, if based solely on levels of symptomatology, may not relate to patients' own perceptions of their QoL.

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This study illustrated that the SEIQoL could be completed by medical populations. It was more sensitive to the health status differences between the groups than were the traditional health related QoL measures.

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The Schedule for the Evaluation of Individual Quality of Life (SEIQoL): a Direct Weighting procedure for Quality of Life Domains (SEIQoL-DW)

Administration Manual

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CONTENTS

1.0 Introduction 3

2.0 SEIQoL-DW Administration 3

2.1 Administration Procedure 4

2.2 Potential Problems in Administration 6

3.0 Scoring the SEIQoL 7

3.1 Recording Scores 7

3.2 Deriving SEIQoL Outcome Data 7

3.3 Presenting Data 8

3.4 Using SEIQoL-DW in Prospective Study Designs 8

4.0 References 9

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SCHEDULE FOR THE EVALUATION OF QUALITY OF LIFE (SEIQoL): A Direct Weighting Procedure for Quality of Life Domains

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1.0 Introduction

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) is an interview-based instrument for the assessment of quality of life (QoL) of the individual. The interview procedure associated with the full version of the SEIQoL (McGee et al, 1991; O'Boyle et al, 1992) requires considerable time to complete (10-30 minutes) and thus may be primarily suitable for research settings or clinical situations where the instrument is being used as part of the process of having the individual consider a range of options or outcomes in evaluating QoL. The SEIQoL has been used with a variety of patient groups, but its applicability may be limited in illnesses which impair cognitive functioning or motivational state. Successful completion of the SEIQoL requires, *inter alia*, insight into the factors which determine one's quality of life, the ability to think abstractly and the ability to make judgments based on information presented in diagrammatic form. Therefore, its use with patients in whom these abilities are impaired may be problematic (Coen et al, 1993).

A direct weighting procedure for QoL domains that is more suitable for routine clinical use than Judgment Analysis (JA) and that may impose fewer demands on individuals with reduced cognitive function has been developed for the SEIQoL (Hickey et al., 1996). Psychometric information on the procedure has been obtained from a healthy adult population (Browne et al, 1997).

The procedure for administering the method is as follows:

Administration of SEIQoL using the Direct Weighting (DW) Procedure

2.0 Administration

The SEIQoL and SEIQoL-DW is administered in the form of a semi-structured interview. The interviewer first elicits the five areas of life considered most important by the individual in determining his/her QoL. The level of satisfaction/functioning in each area is next recorded followed by the SEIQoL-DW task which allows the interviewer to determine the relative importance of each QoL area using the disk provided.

A SEIQoL interview form, SEIQoL-DW disk, pen and non-permanent marker pen are required for the interview.

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2.1 Administration Procedure

Step 1: Introduction

Read the following to the respondent:

"For each of us, happiness and satisfaction in life depends on those parts or areas of life which are important to us. When these important areas are present or are going well, we are generally happy but when they are absent or going badly we feel worried or unhappy. In other words, these important areas of life determine the quality of our lives. What is considered important varies from person to person. That which is most important to you may not be so important to me or to your husband/wife/children/parents/friends (mention one or two of these groups as appropriate) … **and vice versa".**

"I am interested in knowing what the most important areas of your life are at the moment. Most of us don't usually spend a lot of time thinking about these things. Indeed, we often only notice that certain things are important when something happens to change them. Sometimes it is easier to identify what is important by thinking about the areas of life that would (or do) cause us most concern when they are missing or going badly".

Step 2: Eliciting the Five Most Important Aspects of Life (Cues)

Ask the respondent:

"What are the five most important areas of your life at present – the things which make your life a relatively happy or sad one at the moment …. the things that you feel determine the quality of your life?".

If the respondent does not understand what is required the question may be re-phrased in the following ways:

"What parts of your life are most important? …/ What things are most important? …/ 'The most important things in my life are …'."

- Elicit areas NOT individuals, eg. marriage, not wife. Do not give examples.
- The meaning of each cue for the respondent must be documented at this stage on the Cue Definitions Record Form. Establish what the respondent means by each quality of life area named as being important. For example, if an individual were to name 'golf' as a cue, this may relate primarily to leisure activity, but equally it may represent social activity, or physical mobility. Similarly, if 'religion' were named as a cue it might relate to the respondent's spiritual life, but might equally relate to being physically able to get to church, or to the social dimension of meeting one's friends at church. This is particularly important for subsequent review of data, and of obvious relevance when respondents must be re-assessed at some future date in order to ensure that the same cues are being considered.
- Having defined what the respondent means by the cue, it is important that the cue, as labeled by the individual, be used by the interviewer and not the interviewer's interpretation of what the respondent is saying.

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- Should the respondent volunteer cues which resemble 'quality of life' in meaning (eg satisfaction, life quality), the interviewer should probe for more specific cues. Cues such as 'happiness', 'attitude to life', 'morale' are acceptable.

- If it is absolutely necessary to make some suggestions, then read the following list, excluding any cues already mentioned – **family, relationships, health, finances, living conditions, work, social life, leisure activities, religion/spiritual life**. This list is derived from our findings with a range of populations and represents the cues most commonly elicited, in descending order of frequency. It provides for consistency across the interviewers where such prompting is absolutely necessary.

Step 3: Determining Levels

Say to respondent:

"Now that you have named the five most important areas in your life, I am going to ask you to rate how each of these areas are for you at the moment. First I will show you an example of how the rating is done".

Place the Sample Cue Levels Record Form between you and the respondent so that the respondent can clearly see how you carry out the rating.

"First look at this box (indicate)**. As you can see, there are spaces at the bottom in which I can write the five important areas of my life** (indicate), **and there is a scale along the left hand side** (indicate). **The scale ranges from 'worst possible' on the bottom to 'best possible' on the top, and passes through levels such as 'very bad' – 'bad' – 'neither good nor bad' – 'good' – and 'very good' between the two extremes.**

The first important area of my life is X (use a cue not already nominated by the respondent and write it in the first space at the bottom of the rating box) **and if this is going very well at the moment, I can show this by drawing a bar like this** (draw a bar approx. 80mm high). **I am using the scale** (indicate) **to decide how high my bar should be. The nearer I draw the bar to the bottom line, the poorer my rating of that area of my life and the nearer I draw it to the top line, the better my rating of that area of my life. A mark in the middle range would indicate that I am rating life as neither good nor bad, but somewhere in between".**

Now proceed with the ratings for the remaining cues:

Second cue – **"if X_2** (use a cue not already nominated by the respondent and write it in the second space) **is going as well as is possible, I would rate it by drawing a bar like this …"** (draw a bar 100mm high).

Third cue – **"if X_3** (use a cue not already nominated by the respondent and write it in the third space) **is going very badly, I would rate it like this …"** (draw a bar approx. 15mm high).

Fourth cue – **"if X_4** (use a cue not already nominated by the respondent and write it in the fourth space) **is just all right, or 'fifty/fifty', I would rate it like this …"** (draw a bar approximately 50mm high).

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Fifth cue – **X_5** (use a cue not already nominated by the respondent and write it in the fifth space) – (draw a random rating).

"This provides a picture of life as I might think of it at the moment".

Step 4: Elicit Rating of Present Life

Place the Cue Levels Record Form between you and the respondent. Write the respondent's five cues in the appropriate spaces under the box. Give the respondent a pen or pencil.

Say to the respondent:

"Now I want you to rate the five most important areas of your life, as you see presented here (indicate). **Firstly, draw a bar which represents how you would rate yourself on each of these areas at the moment. As in the example I've just shown you, the nearer you draw the bar to the bottom line, the poorer you are rating that area of your life and the nearer you draw it to the top line, the better you are".**

Have respondent draw bars.

Step 5: Direct Weighting Procedure

Say to respondent:

"I would like you to show me how important the five areas of life you have nominated are in relation to each other, by using this disk (indicate SEIQoL-DW). **People often value some areas in life as more important than others. This disk allows you to show me how important each area in your life is by giving the more important areas a larger area of the disk, and the less important areas a smaller area of the disk. In my life, for example, X** (name cue not already chosen by respondent) **is about this important** (manipulate disk so that X represents 30% of space available). **X_2 however is less important than X, so it has only this much of the pie** (manipulate disk so that X_2 represents 20% of the space available). **X_3 on the other hand is more important than X, so it has this much of the pie** (manipulate DWP so that X_3 represents 40% of space available). **Finally, X_4 and X_5 are the least important areas of life for me, and I value them about the same** (manipulate disk so that X_4 and X_5 represent 5% each of space available). **Now thinking about the five areas of life you have mentioned** (write the name of each cue along the cut edge of one of the 5 coloured disks with a non-permanent marker [disks may also be marked with stick-on 'post-it' labels indicating the cues if preferred]). **I would like you to show me how important these areas are in relation to each other by moving the disks around until their relative size represents your view of their importance".**

2.2 Potential Problems in Administration

The following are the problems most commonly encountered in SEIQoL-DW administration.

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- **<u>Nominating Important Life Areas</u>:**

  The respondent cannot think of 5 cues.

  Suggested Solution: use prompt list provided.

- **<u>Determining Cue Levels</u>:**

  The respondent conceives the task as drawing bars in terms of their importance rather than in terms of how these areas are for them at the moment.

  Suggested Solution: Remind the respondent that the task is to "rate how each of these areas are for you at the moment".

- **<u>Determining Cue Weighting</u>:**

  The respondent conceives the task as dividing up the pie diagram in terms of current functioning in that area.

  Suggested Solution: Remind the respondent that the task is to indicate how important each of the 5 areas are at present relative to each other.

3.0 Scoring the SEIQoL

3.1 Recording Scores

Record on the Interview Record Form:

- The length of time the respondent took to complete the task
- The interviewer's rating of the respondent's understanding of the method
- Whether the interviewer felt that the respondent become fatigued/bored during the task
- The interviewer's overall rating of the validity of the information obtained
- Scores of the weights assigned to SEIQoL-DW for each cue

3.2 Deriving SEIQoL Outcome Data

(i) Cue labels and their definitions
(ii) Cue levels
(iii) Cue weights
(iv) The SEIQoL Index

(i) Cue Labels and their Definitions

During Step 2 (eliciting the five most important aspects of life), the meaning of each cue for the respondent is summarized on the Cue Definitions Record Form, together with the label that the respondent used for each cue. For example, different respondents may use "religion" as a cue label, but it can have various meanings: a spiritual activity; a social activity (meeting friends at services) or a physical activity reflecting mobility (being able to walk to services).

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The definition is important for subsequent understanding of what was meant by the cue label. It is also important in summarising cues from a number of respondents for grouped data presentation.

(ii) Cue Levels

The cue levels are elicited during Step 3 when the respondent draws five bars on the Cue Levels Record Form. Levels are scored by measuring the vertical height of each bar in millimetres. This yields five scores which are independent continuous measurements, ranging from 0 to 100. They can be analysed using parametric statistical methods.

(iii) Cue Weights

To calculate weights from SEIQoL-DW, align edge of green disk tab with the '0' (zero) gradation and note the weight (0-100) given to each of the 5 life areas by reading the amount of disk space assigned against the gradation on the outer edge of the disk. Divide each weight by 100 since the weights when calculating the SEIQoL Index range from 0.00-1.00 in order that the overall Index (levels X weights) sum from 0-100.

(iv) The SEIQoL Index

The SEIQoL is intended primarily as an individual measure. Where group comparisons are required, a global index can be calculated which may be used in within-subject or between-subject study designs. As the index is a continuous measure ranging from 0 to 100 it can be analysed using parametric statistical methods. Having obtained levels and weights for each of the five cues, as described previously, the SEIQoL Index is calculated as follows:

- For each cue multiply the level by the weight, then sum these products across the five cues: **SEIQoL Index = $\sum$ (levels x weights)**

Care should always be taken in interpreting the index, as it is the sum of the products of individual cue levels by cue weights, each of which may vary independently. The index should be interpreted in the context of the pattern of levels and weights generated for each respondent.

3.3 Presenting Data

The data from each individual respondent can be presented in tabular form giving the elicited cues, the levels and the weights. For grouping data SEIQoL Index scores may be presented (cf. McGee et al., 1991, O'Boyle et al., 1992).

3.4 Using SEIQoL-DW in Prospective Study Designs

In prospective study designs, or in situations where SEIQoL-DW is employed over time to evaluate an intervention, recommended practice is that new cues are elicited at each assessment. Cues nominated at the initial assessment should then be provided to the individual and the SEIQoL-DW procedure gone through again, in order to facilitate direct comparison between initial and subsequent assessments.

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CUE DEFINITIONS RECORD FORM

DESCRIPTION OF CUE **CUE LABEL**

1. _____

_____

_____ _____

2. _____

_____

_____ _____

3. _____

_____

_____ _____

4. _____

_____

_____ _____

5. _____

_____

_____ _____

(Tick any cues elicited by reading list to person)

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CUE LEVELS RECORD FORM

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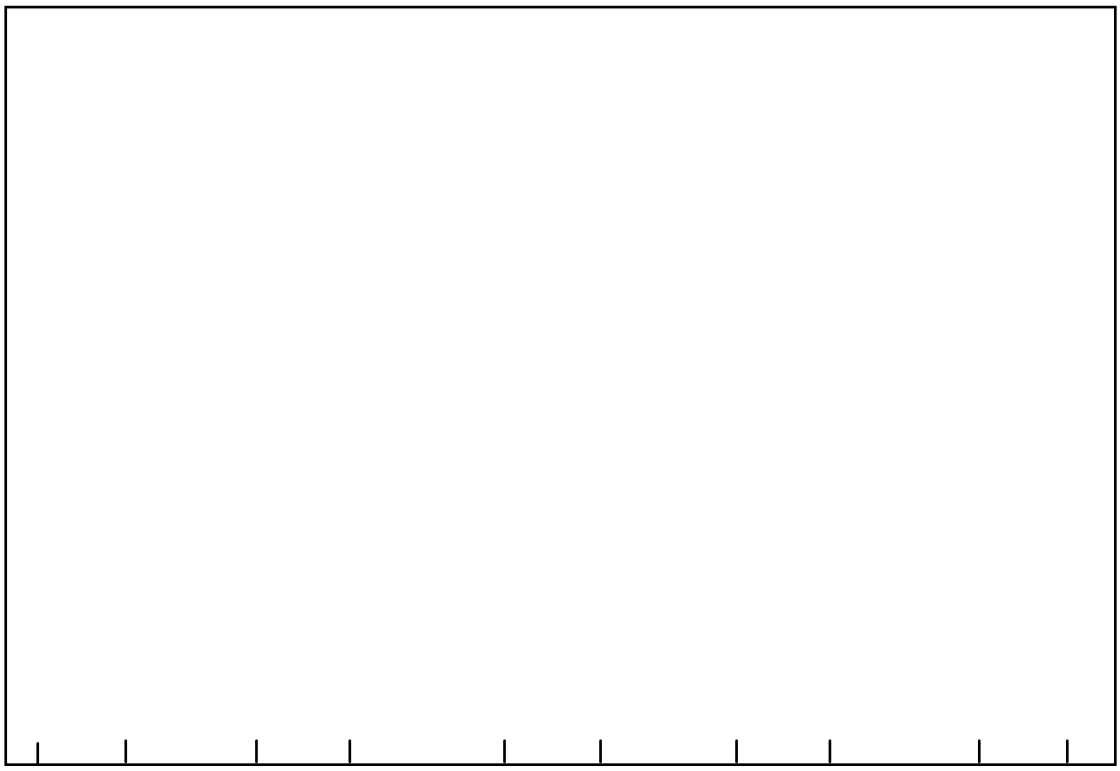

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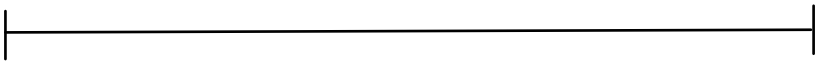

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INTERVIEW RECORD FORM

1. TIME TAKEN _____

2. UNDERSTANDING OF METHOD

- Not Understood _____
- Poor/Uncertain Understanding _____
- Understood _____

3. FATIGUE/BOREDOM

- None _____/_____
- Some _____/_____
- A Lot _____/_____

4. OVERALL VALIDITY OF INFORMATION (in light of 2 & 3 above)

Definitely Invalid _____

Uncertain _____

Valid _____

5. WEIGHTS ASSIGNED TO CUES

Cue 1: Weight (%) _____

Cue 2: Weight (%) _____

Cue 3: Weight (%) _____

Cue 4: Weight (%) _____

Cue 5: Weight (%) _____

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HYPOTHETICAL CASE FORMS

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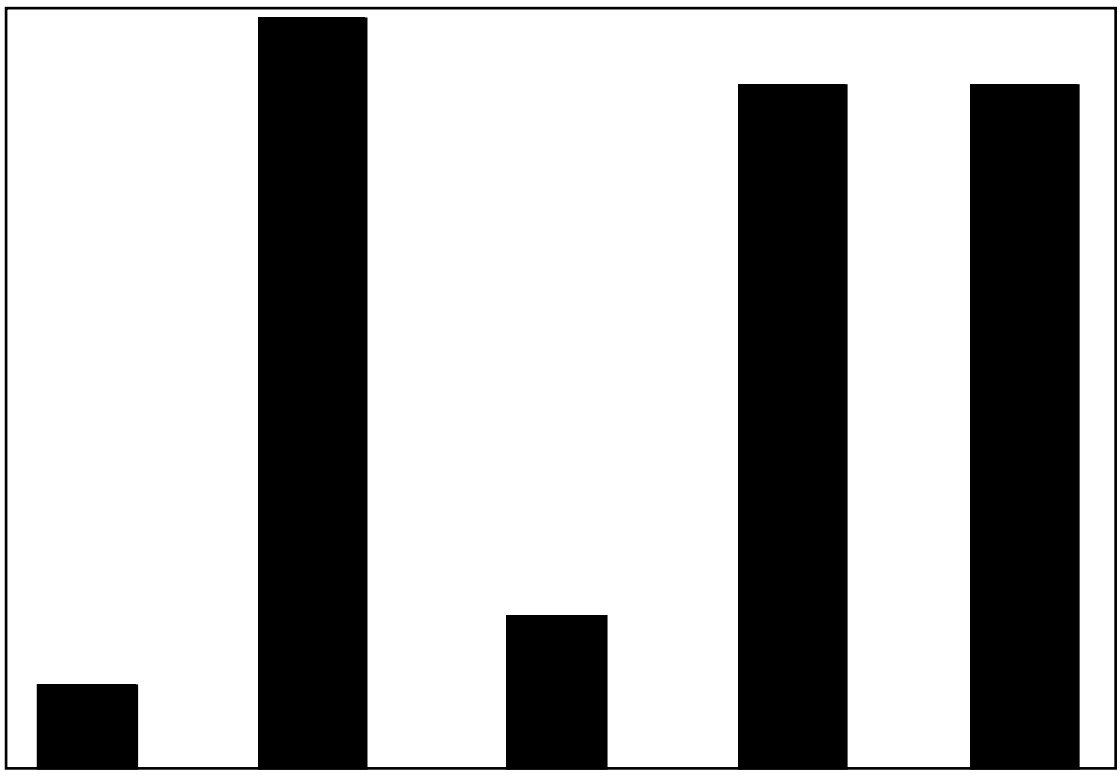

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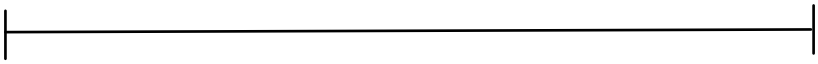

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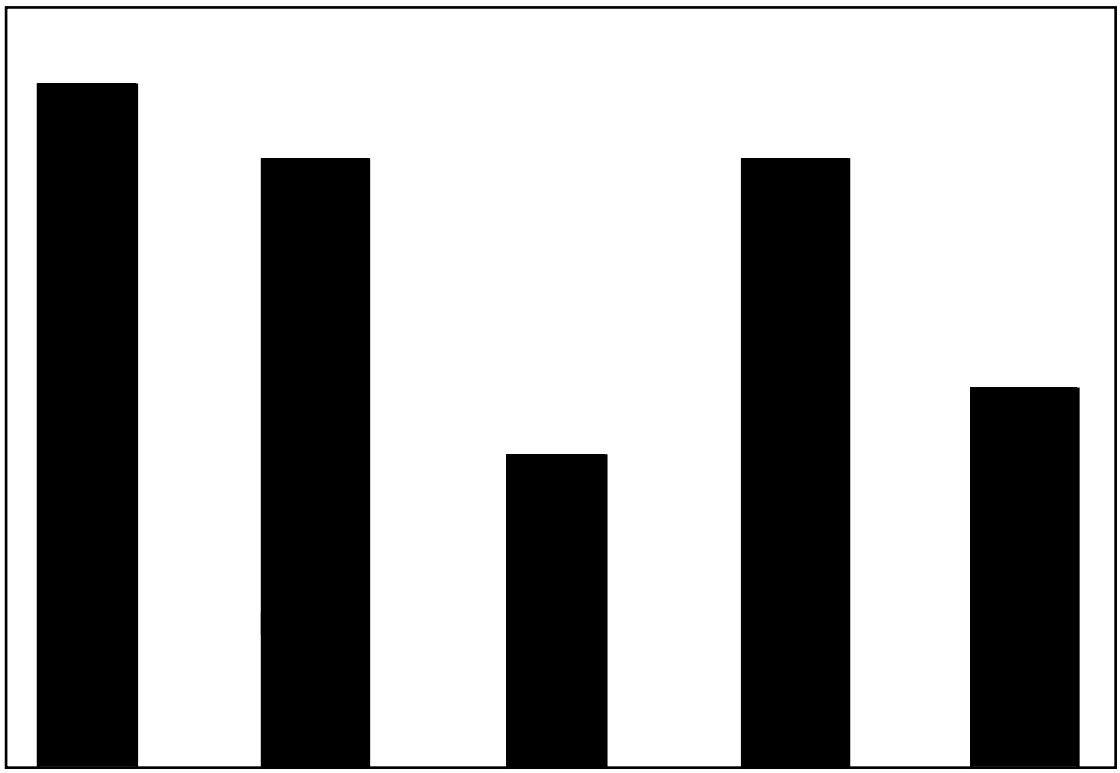

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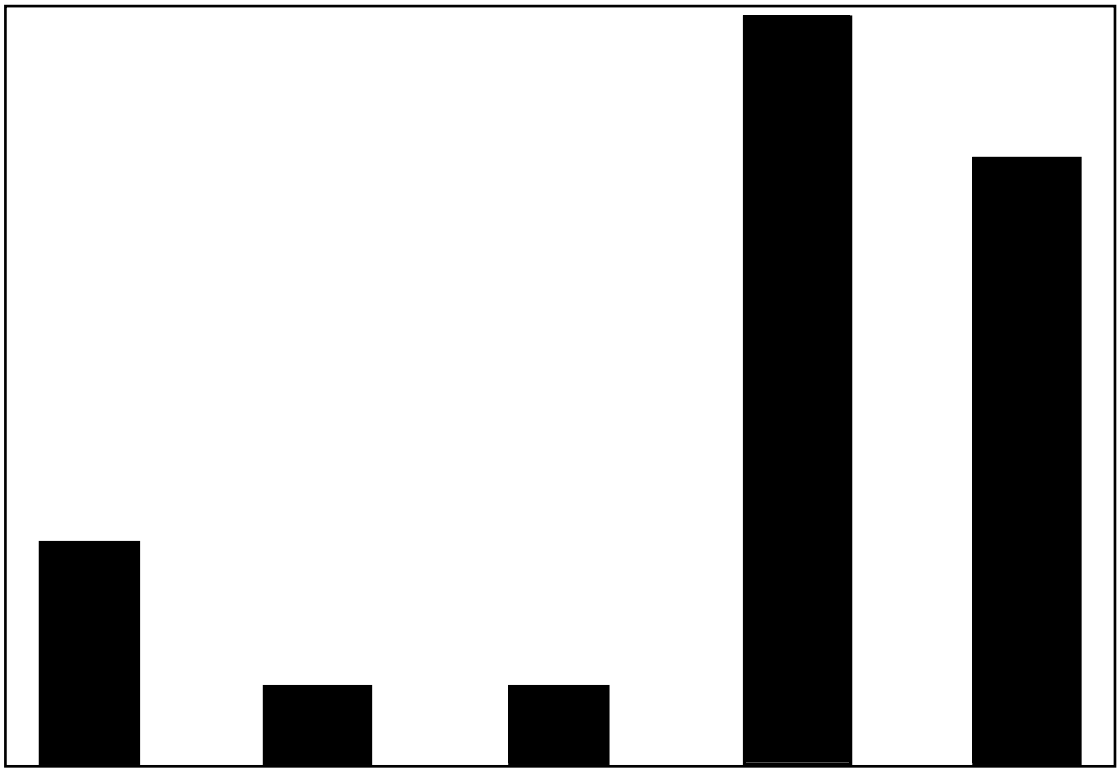

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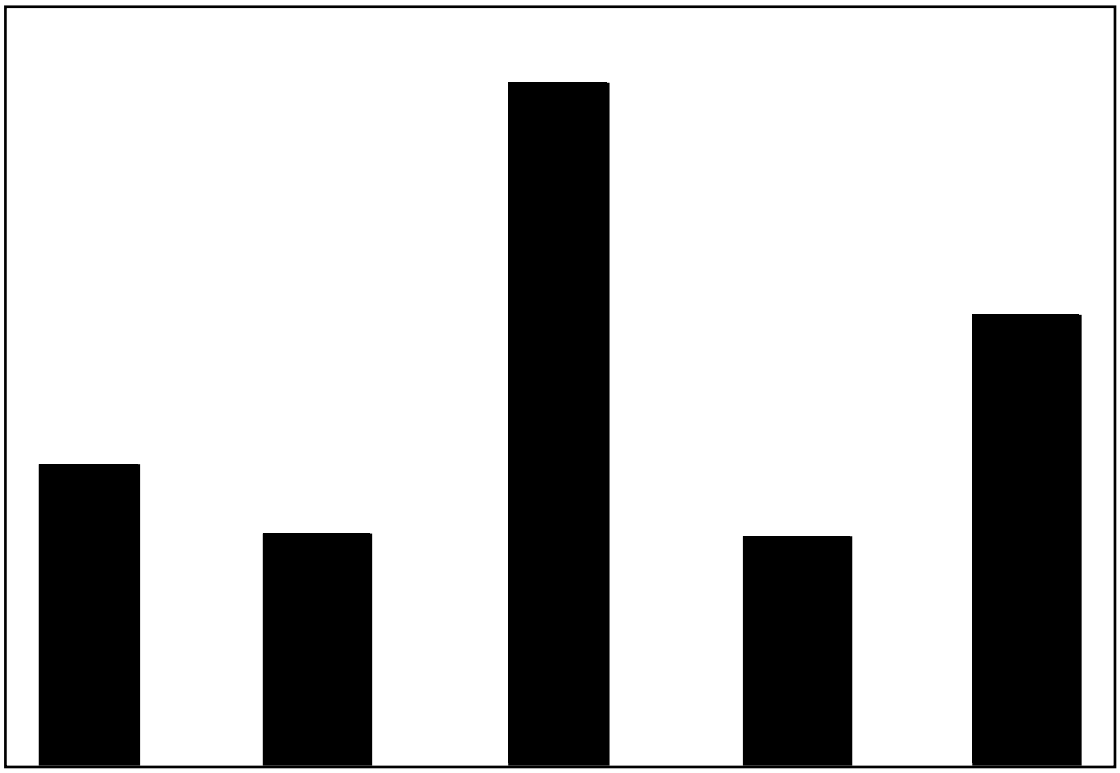

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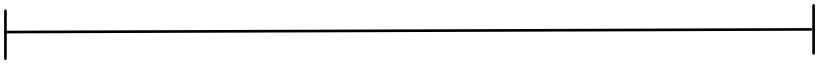

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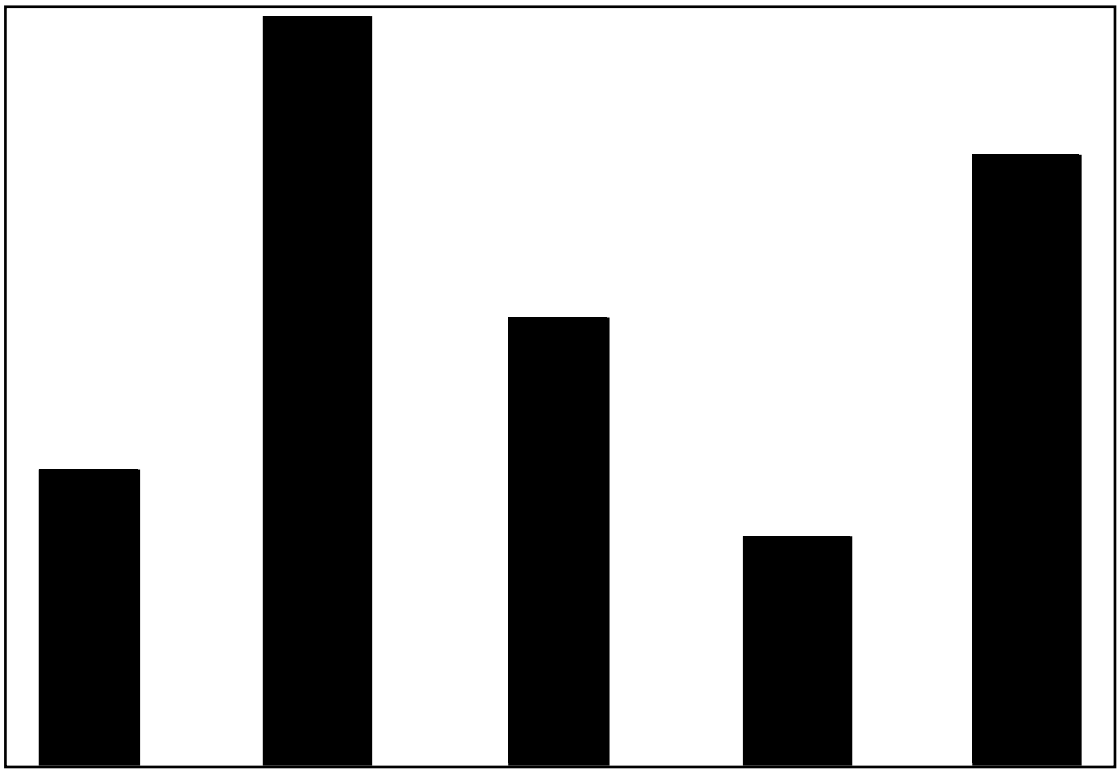

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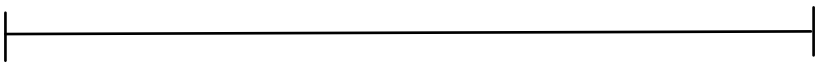

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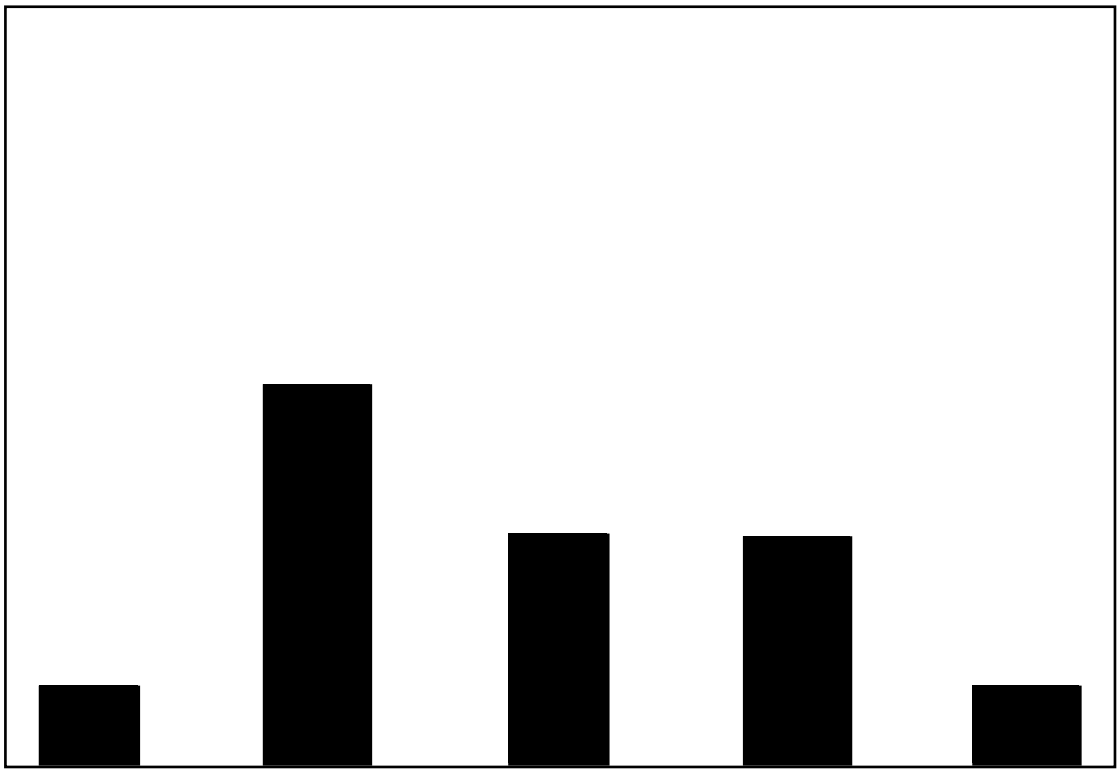

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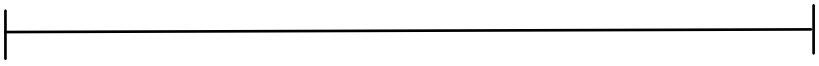

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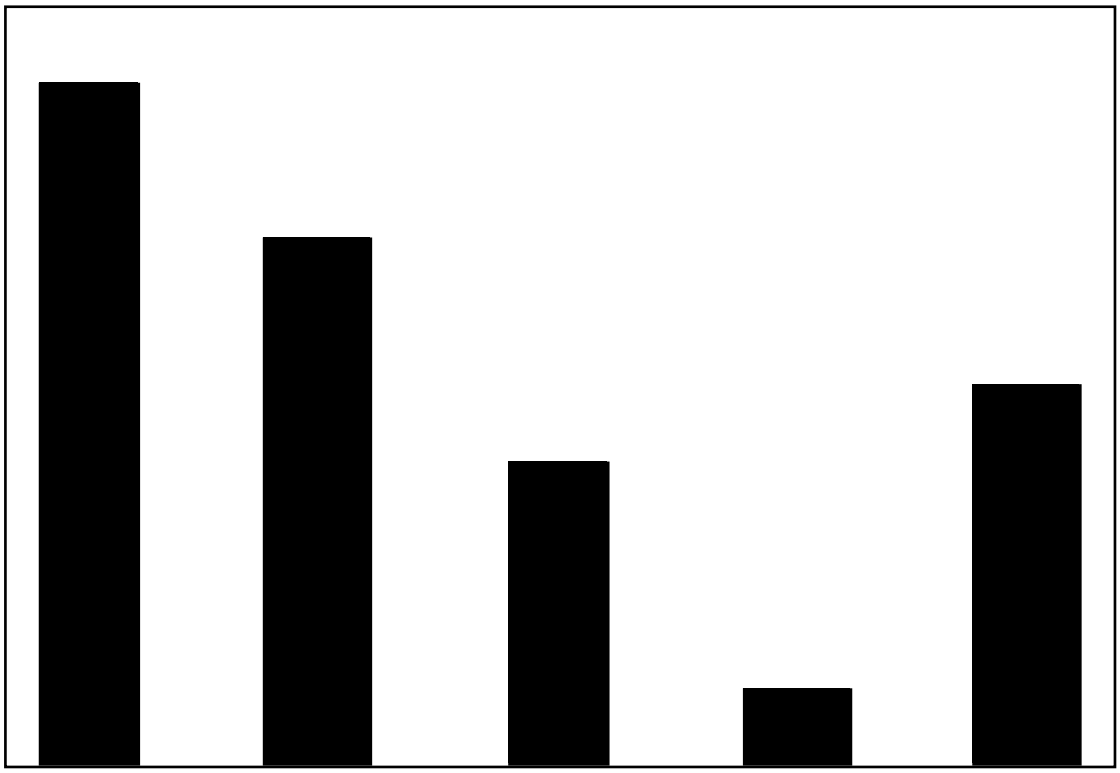

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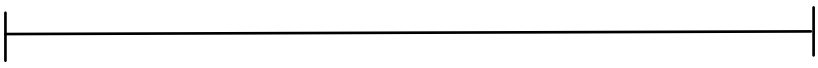

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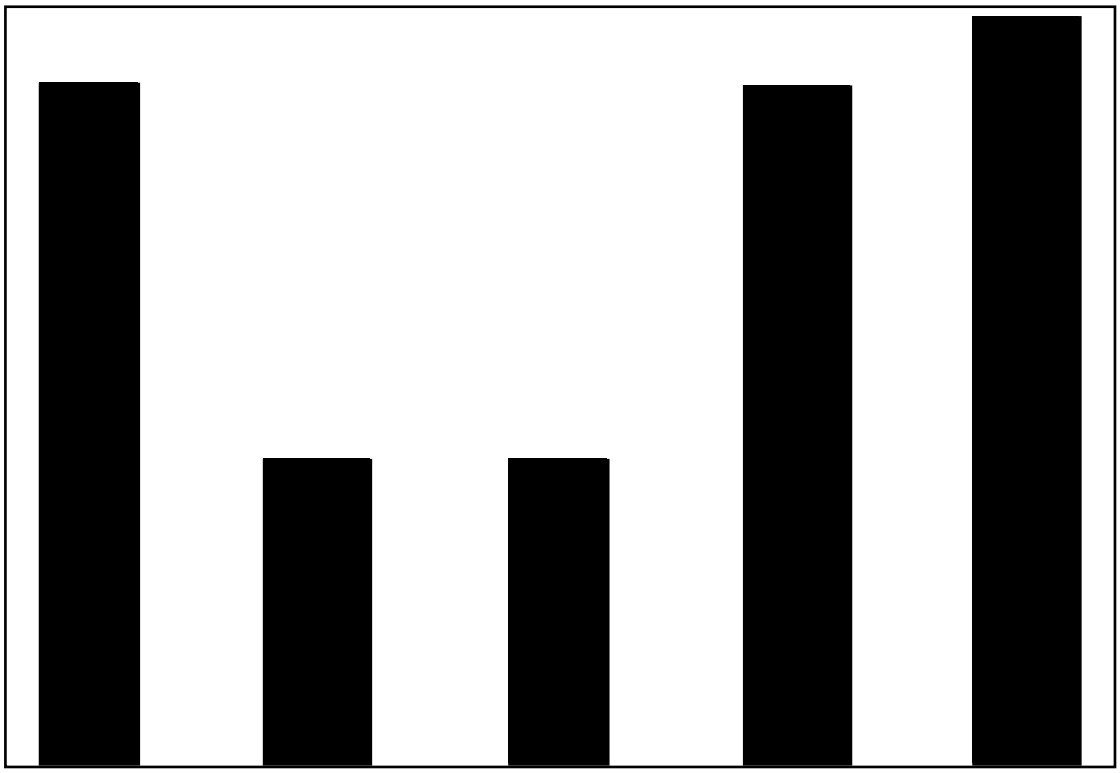

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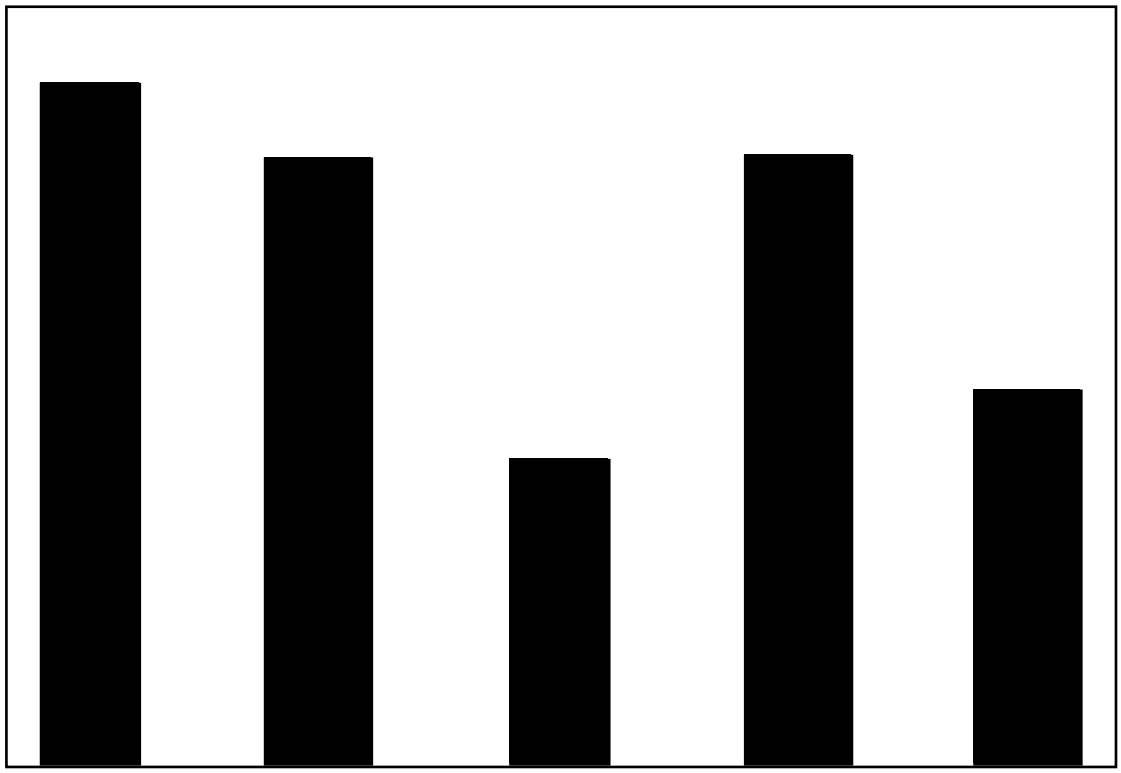

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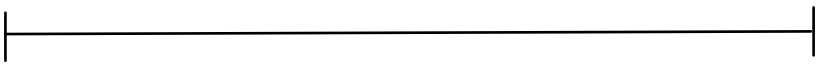

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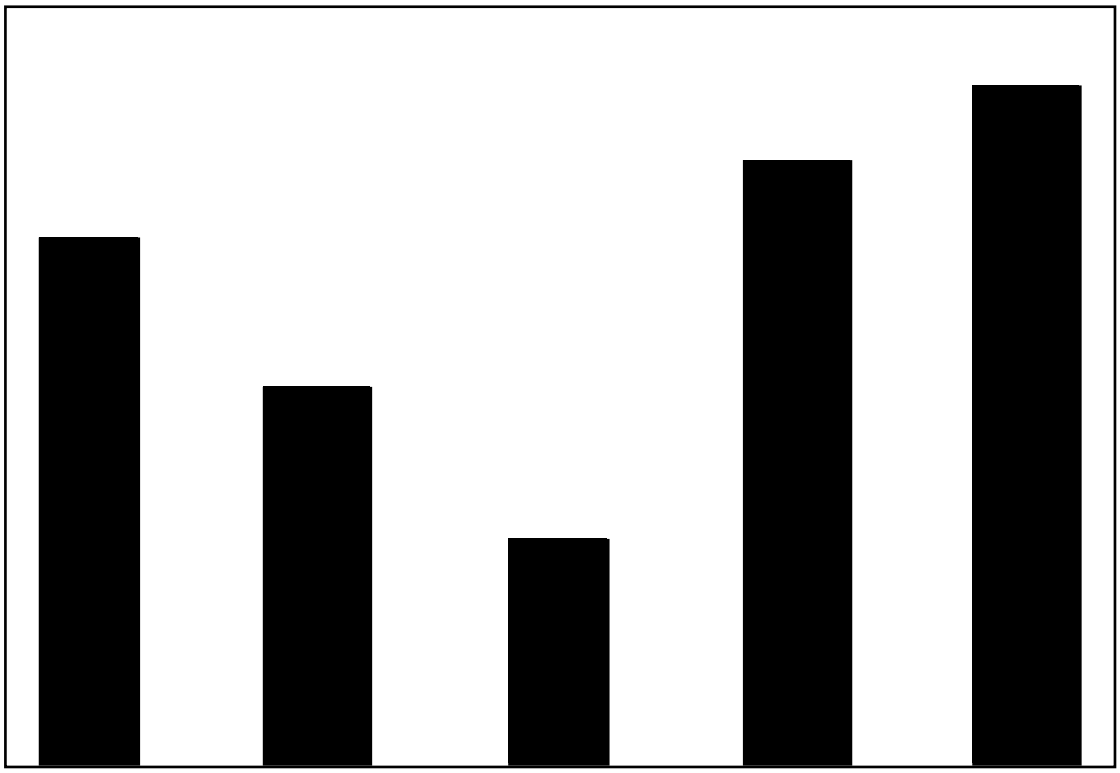

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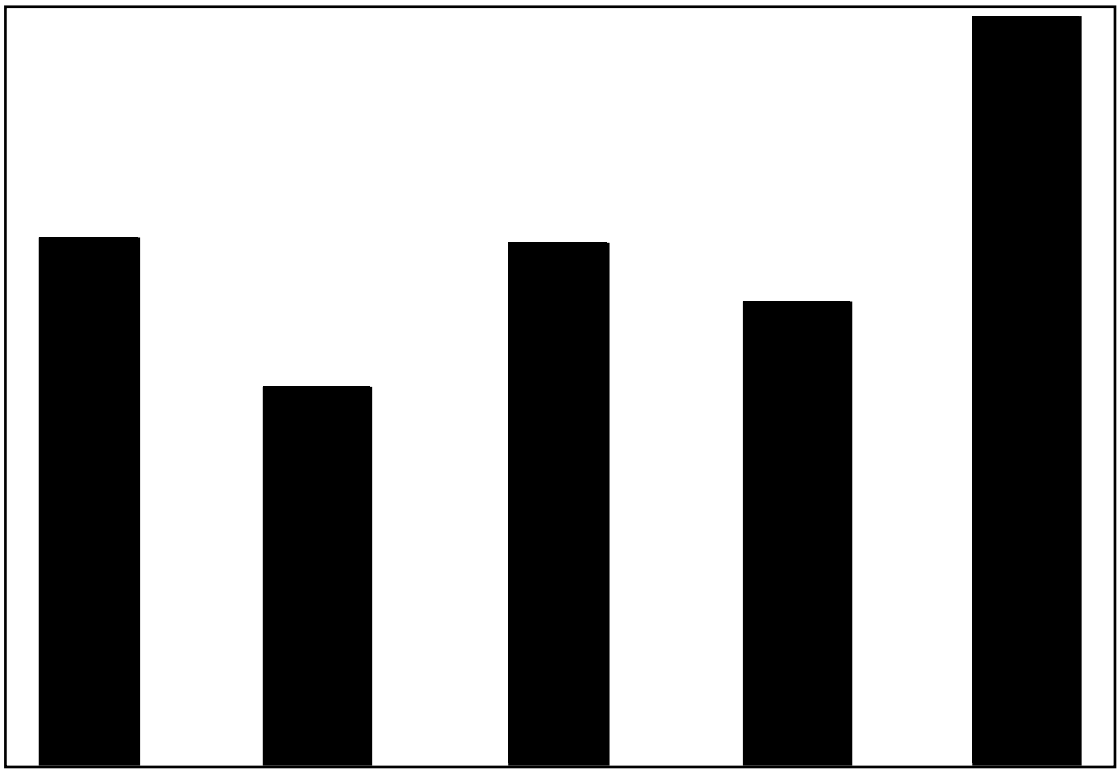

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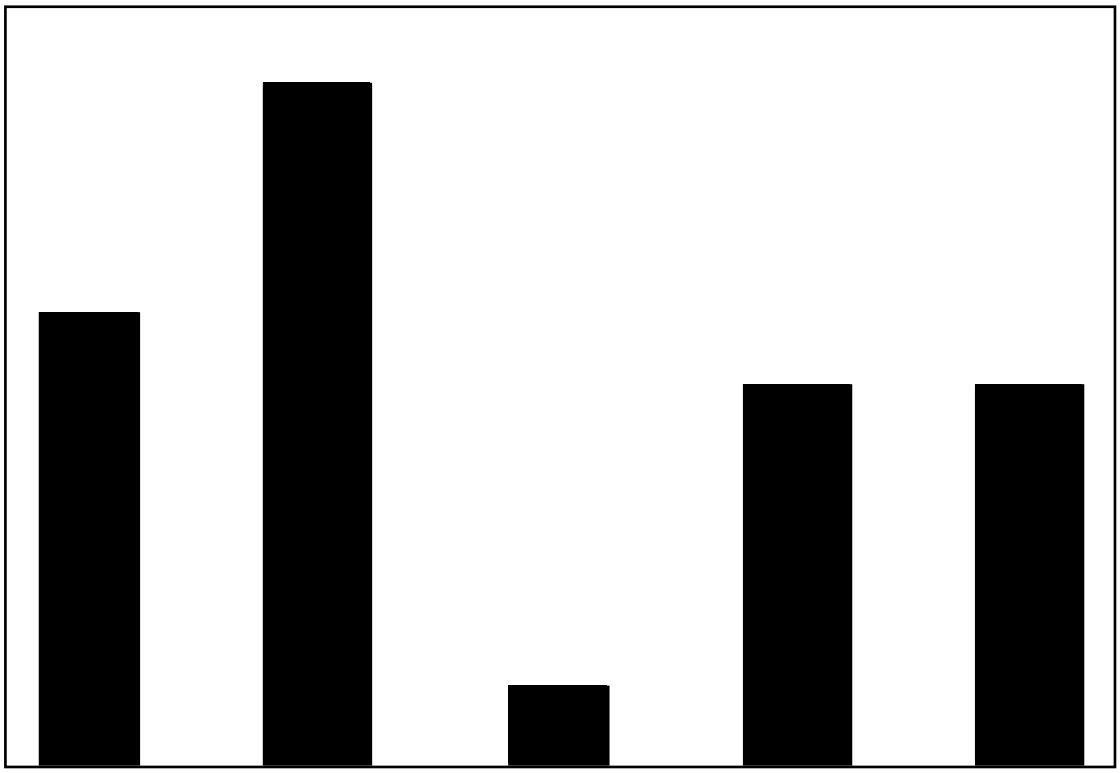

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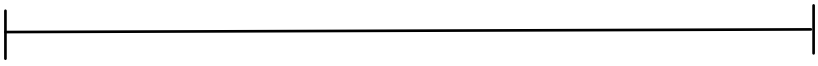

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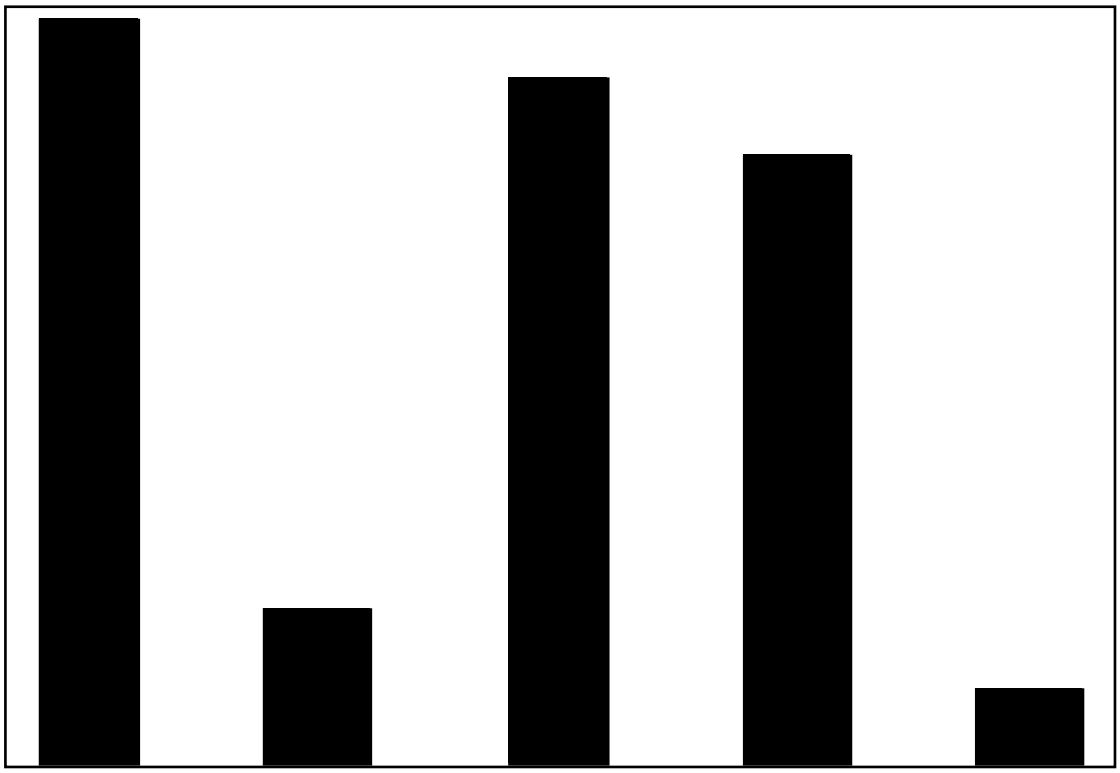

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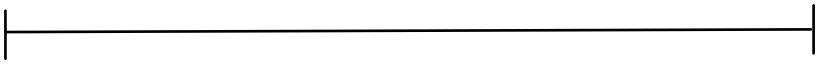

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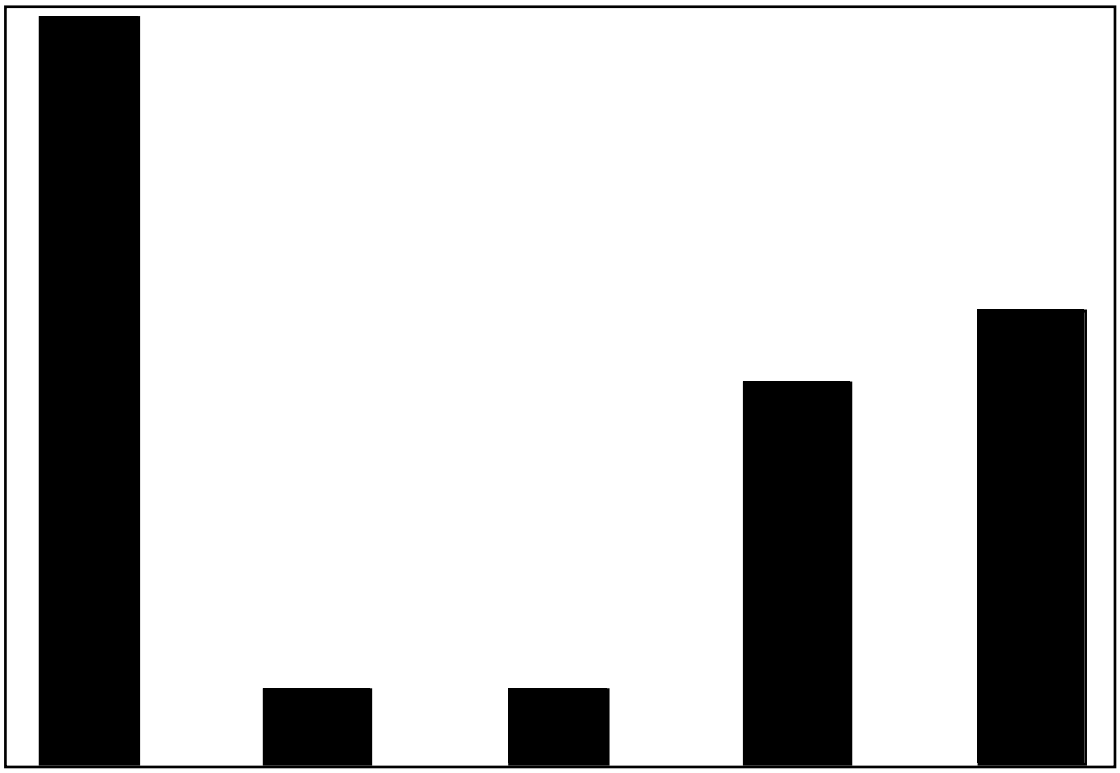

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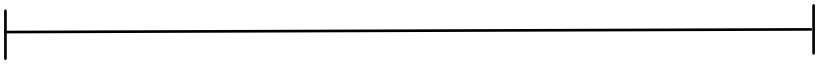

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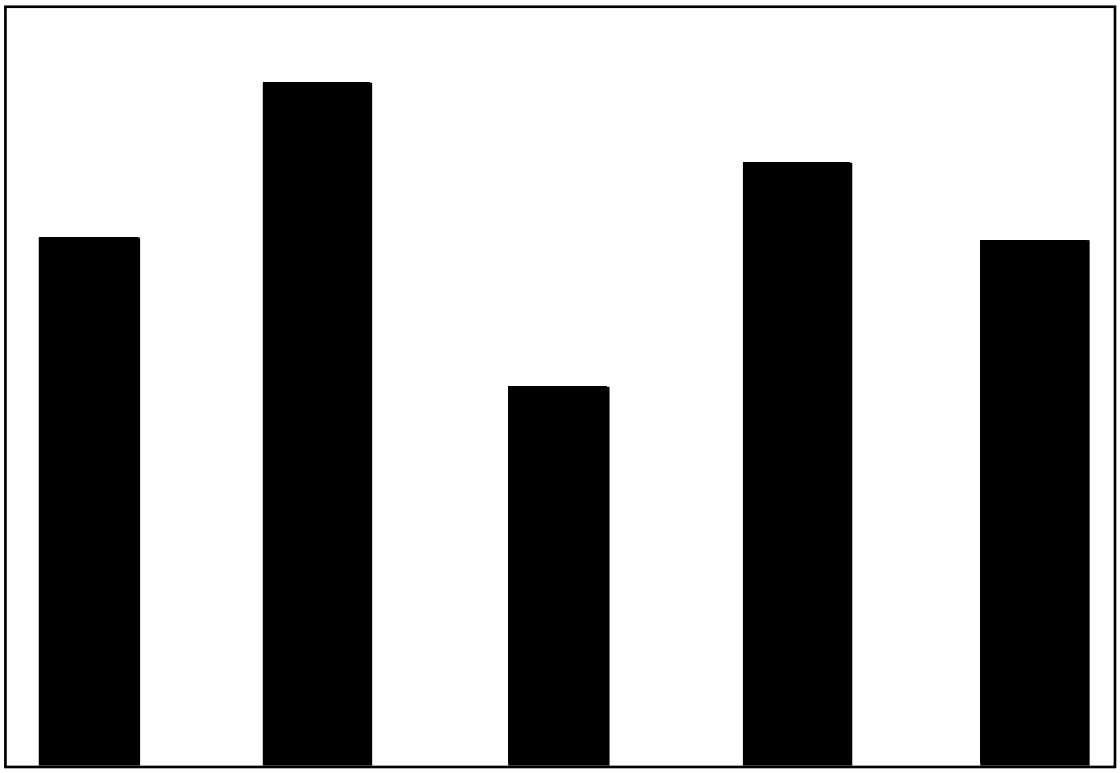

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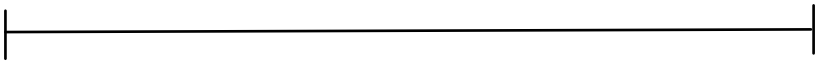

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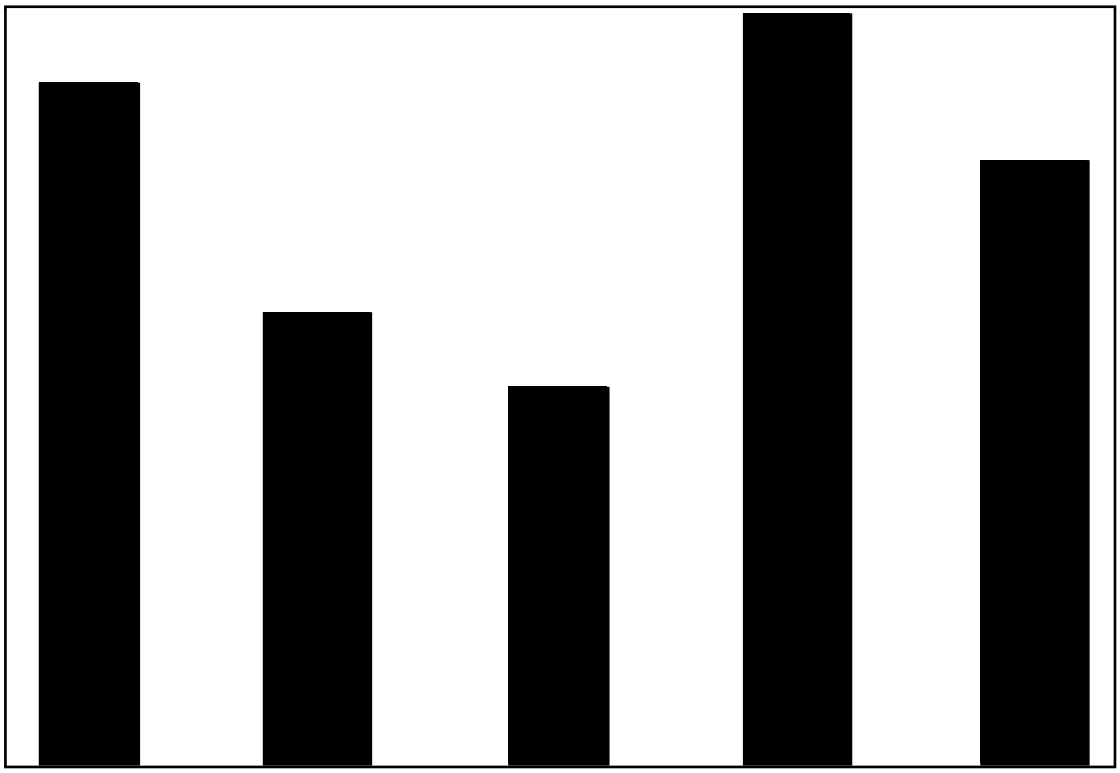

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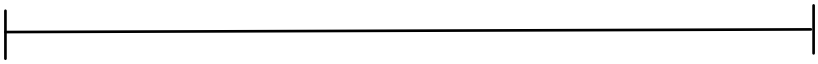

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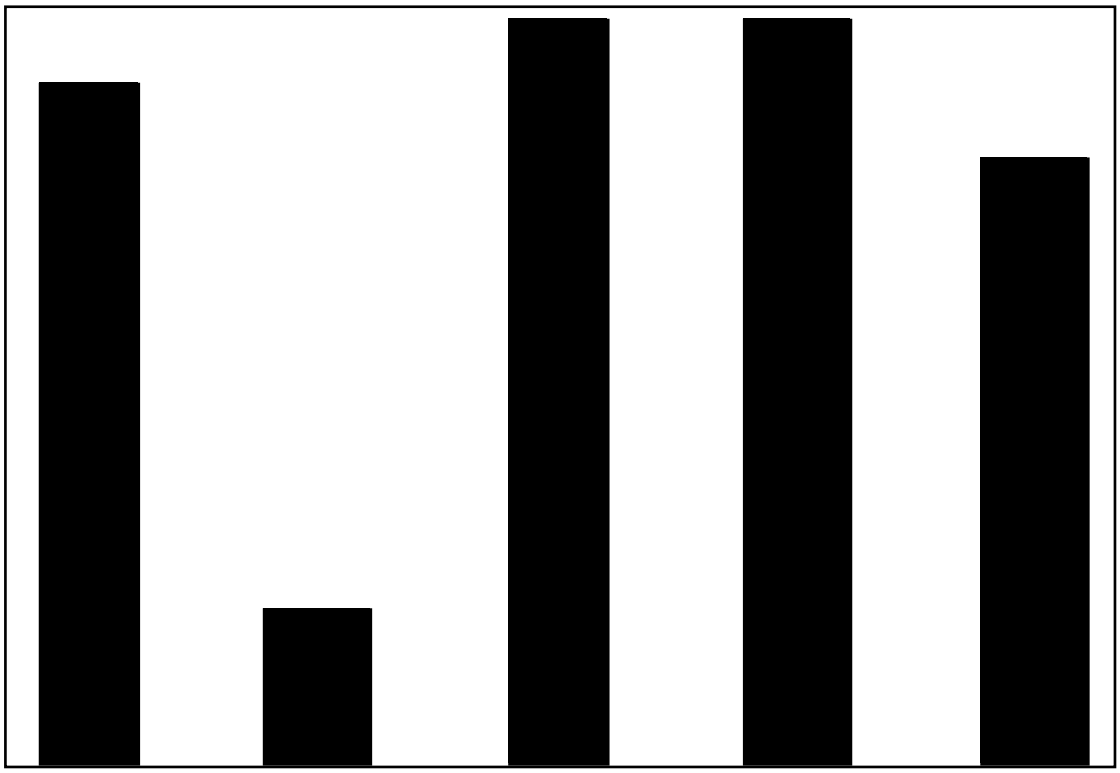

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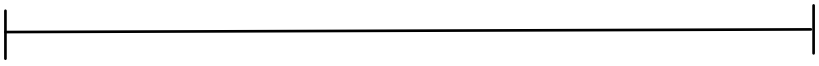

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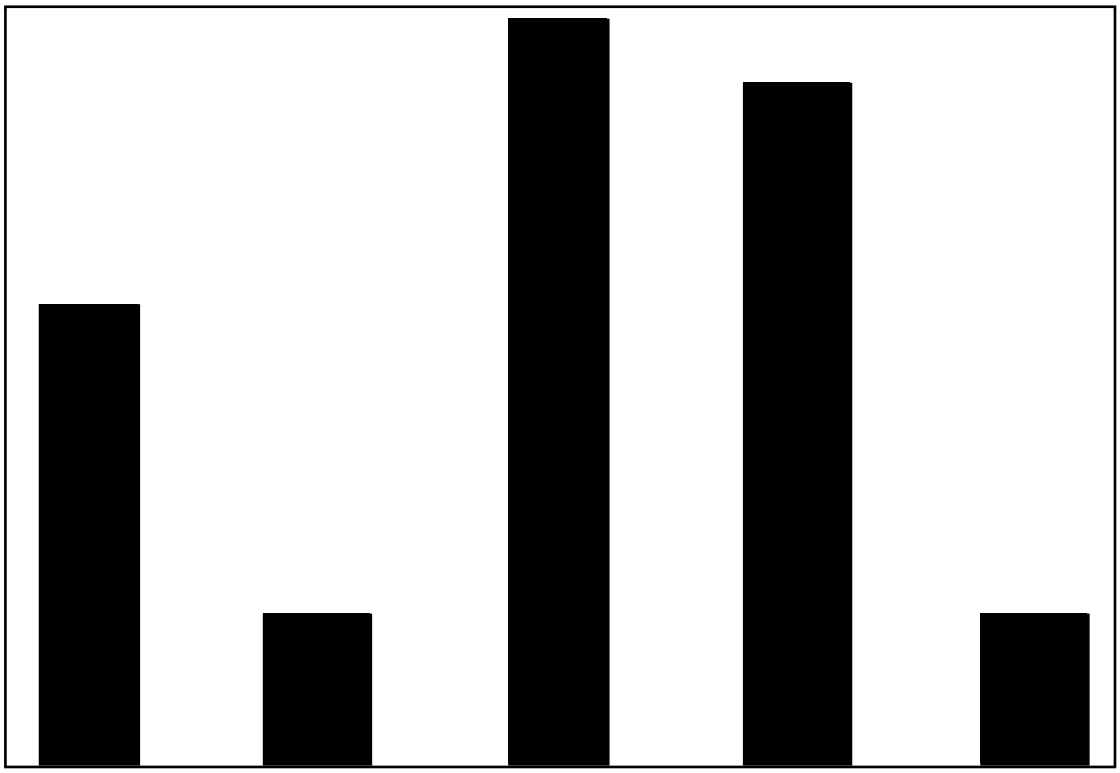

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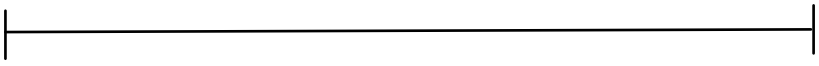

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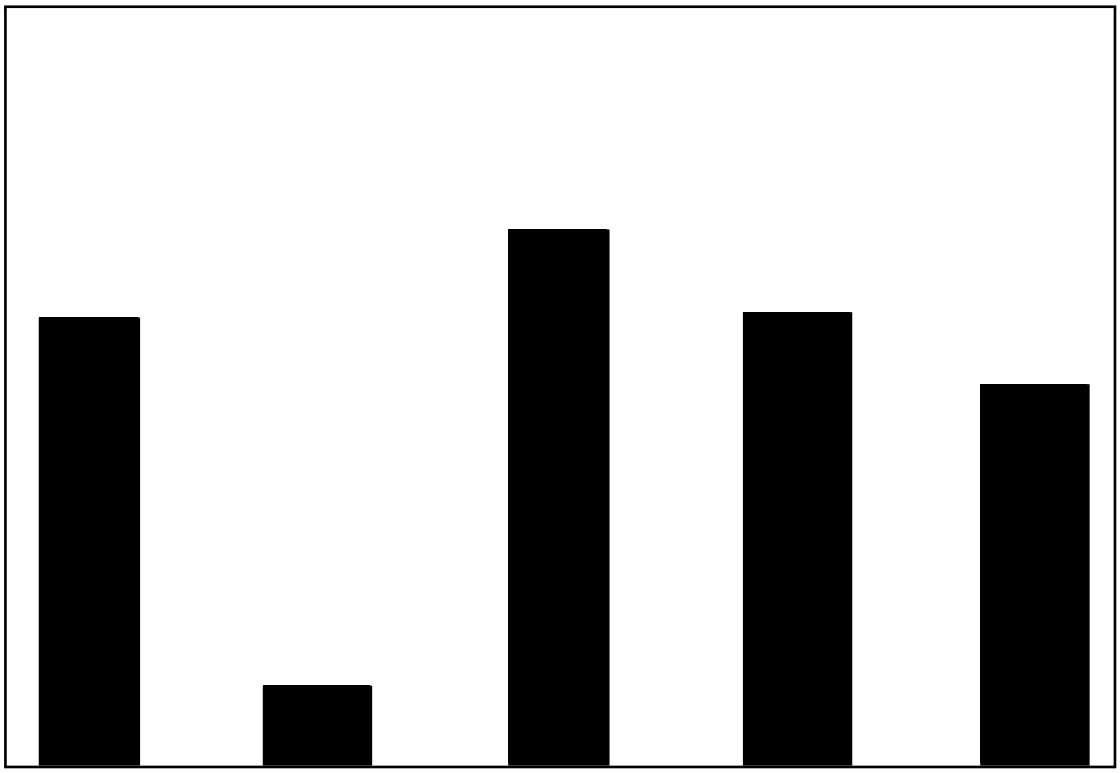

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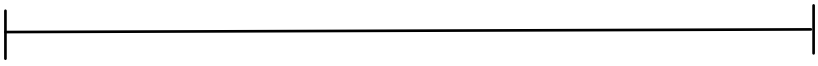

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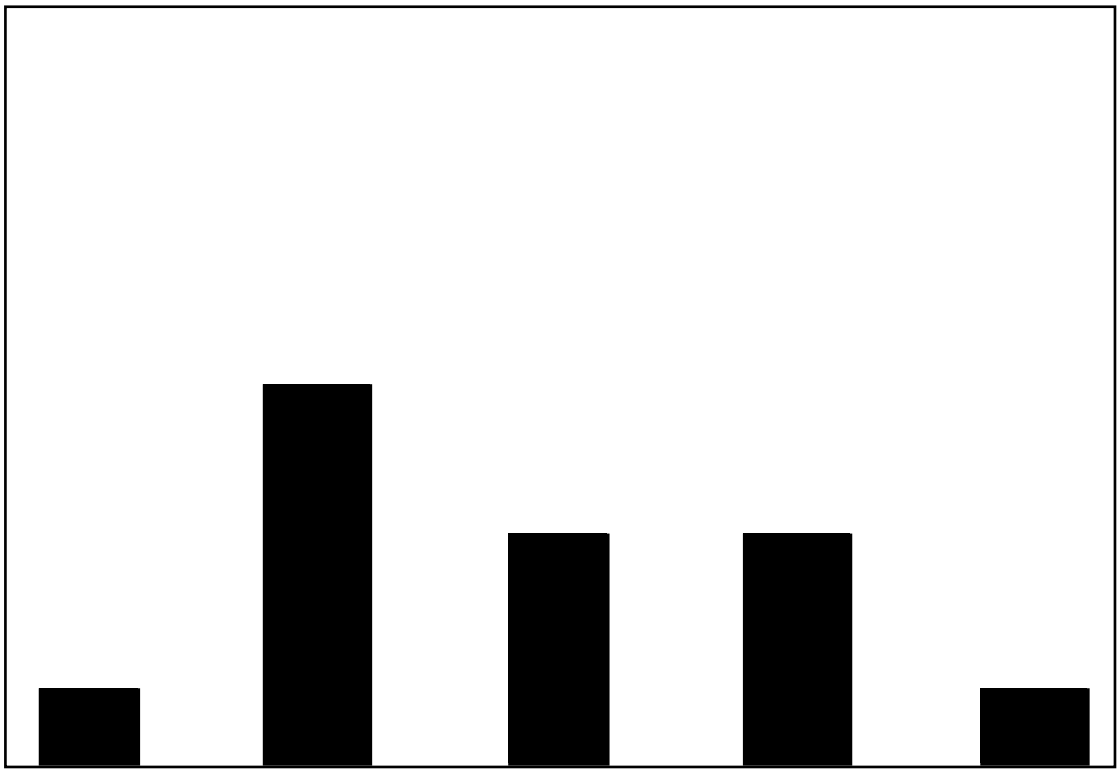

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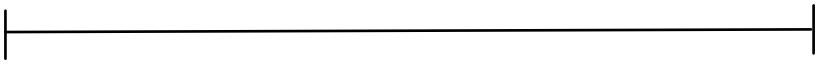

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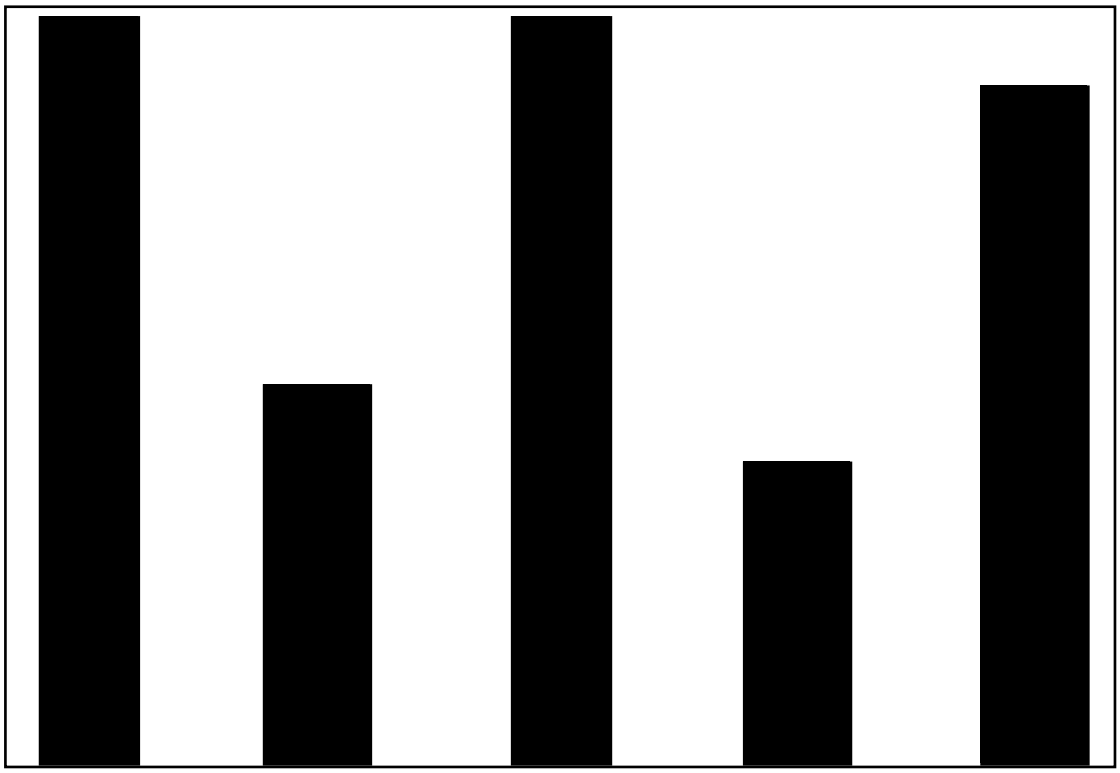

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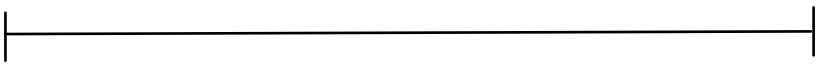

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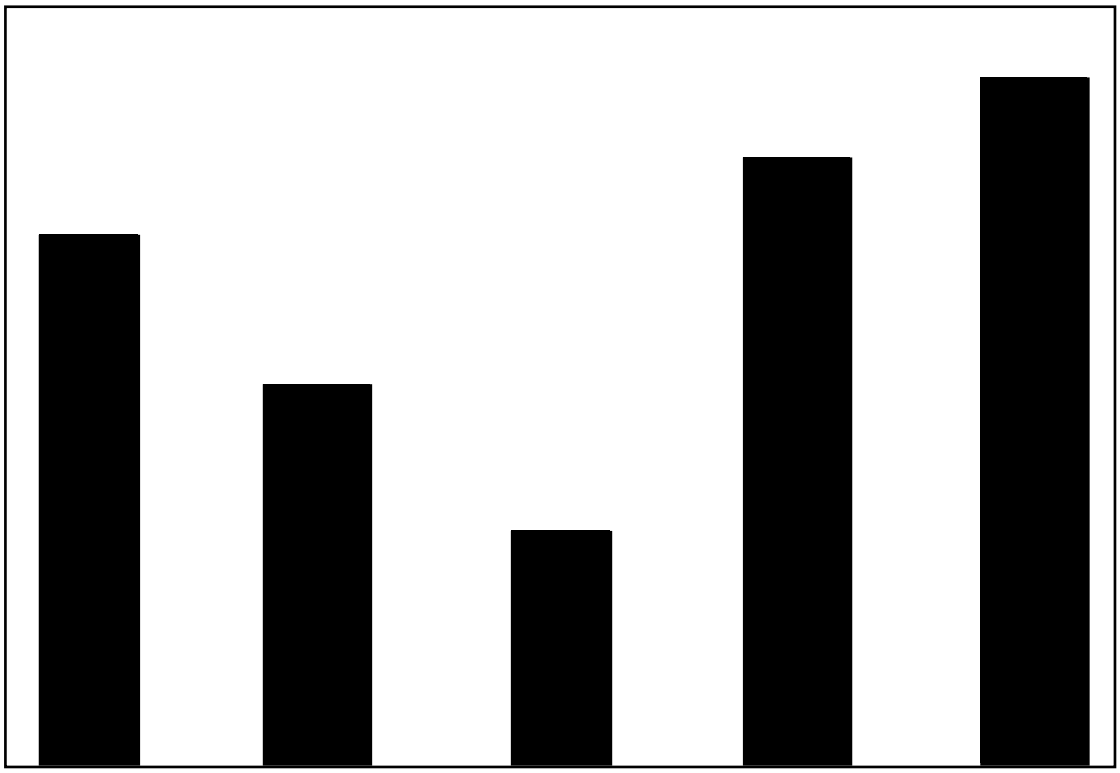

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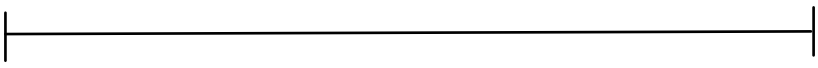

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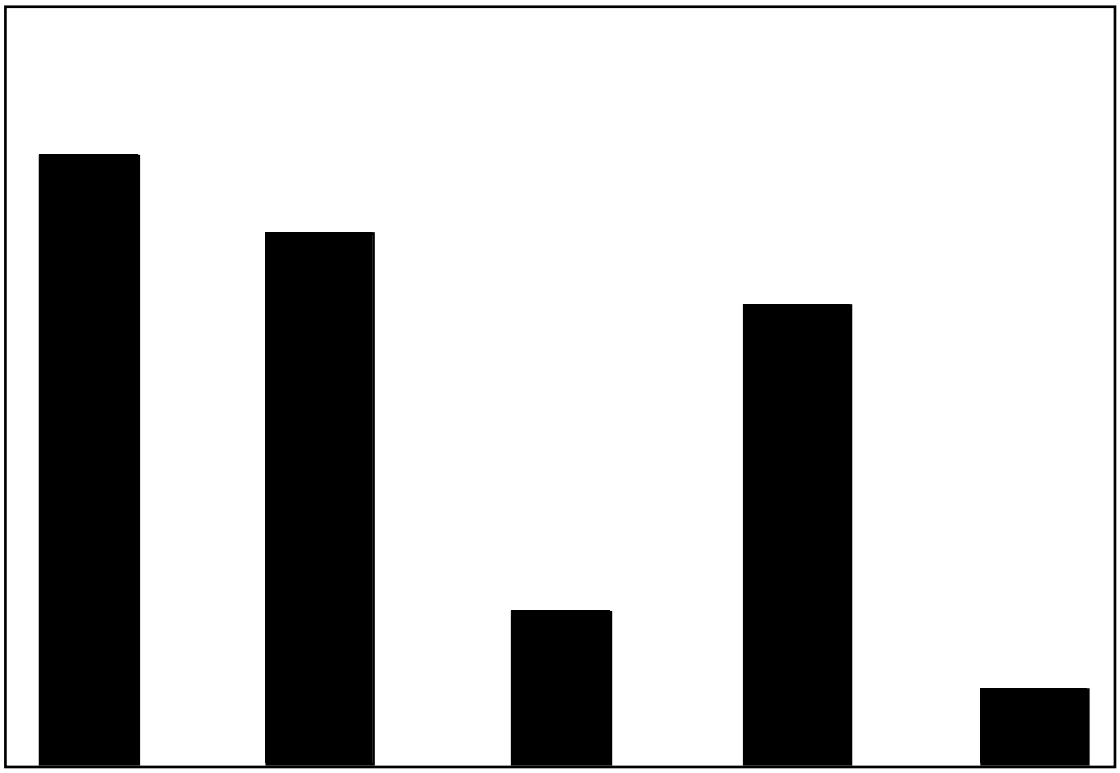

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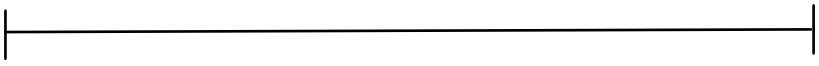

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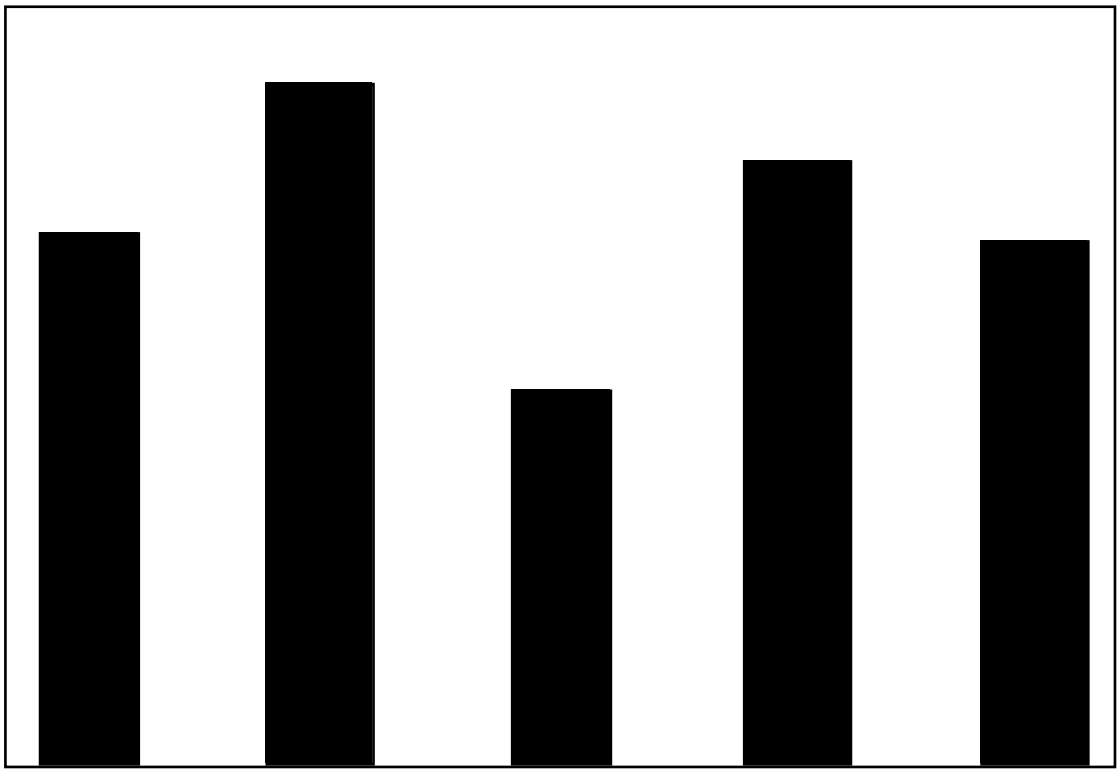

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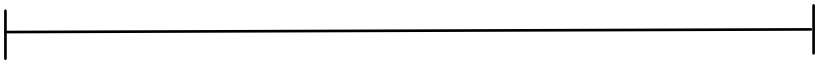

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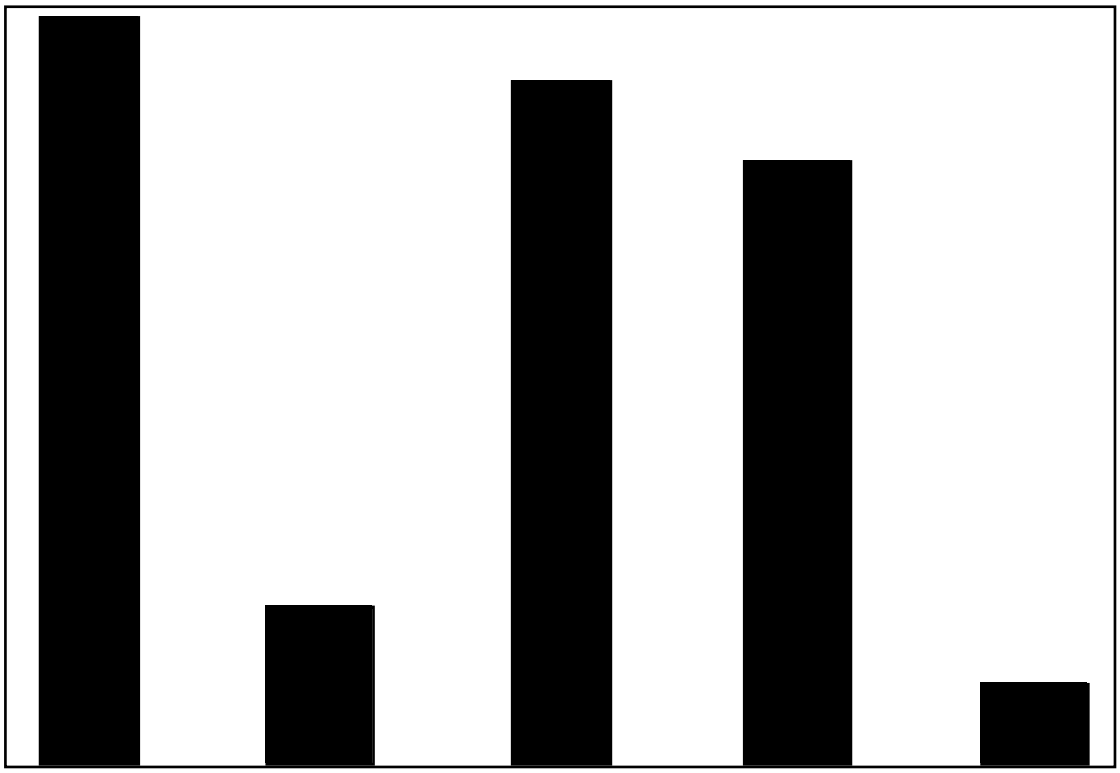

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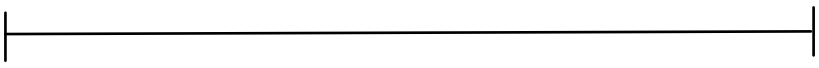

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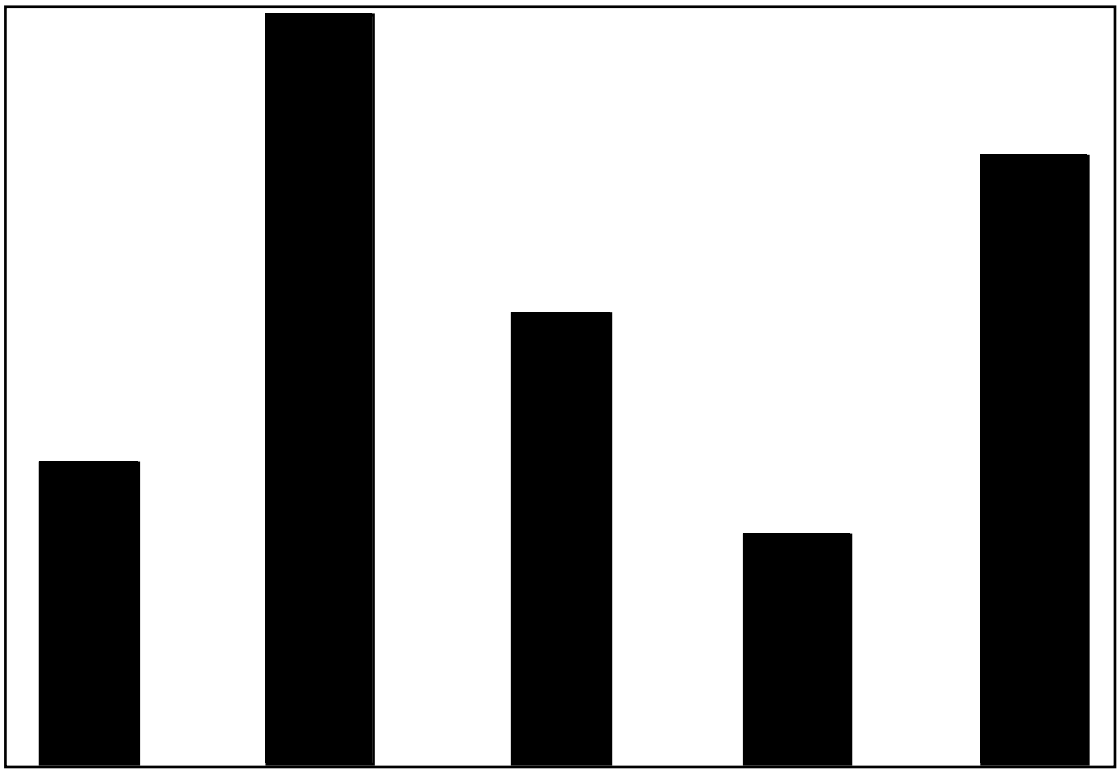

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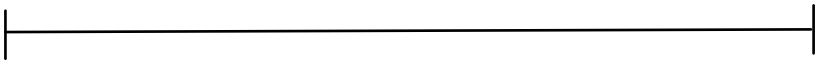

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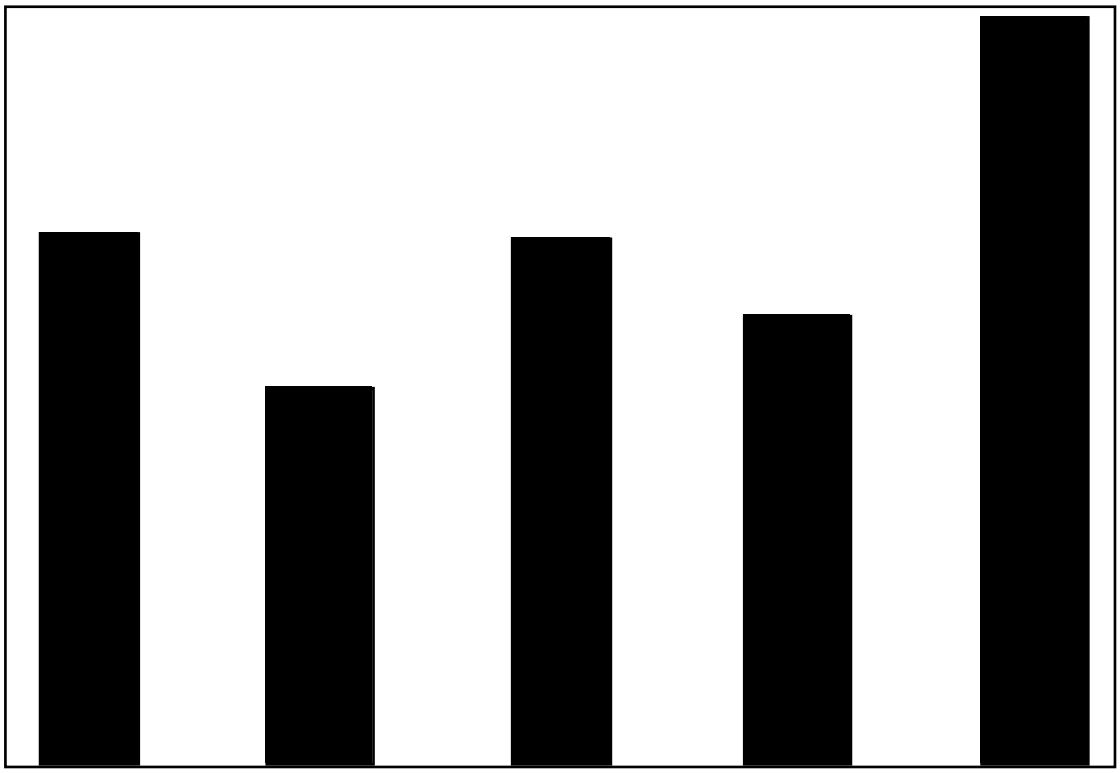

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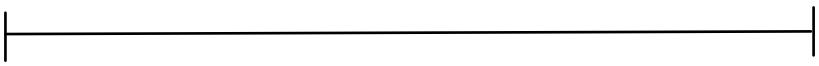

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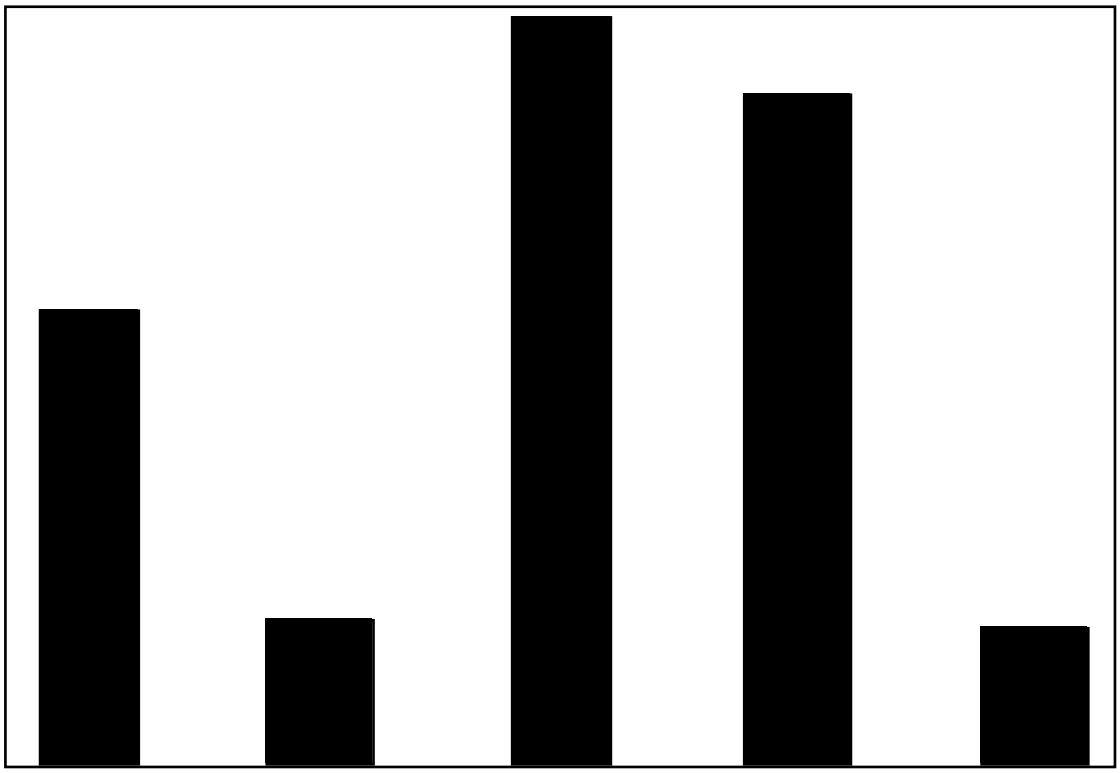

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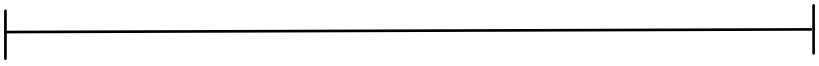

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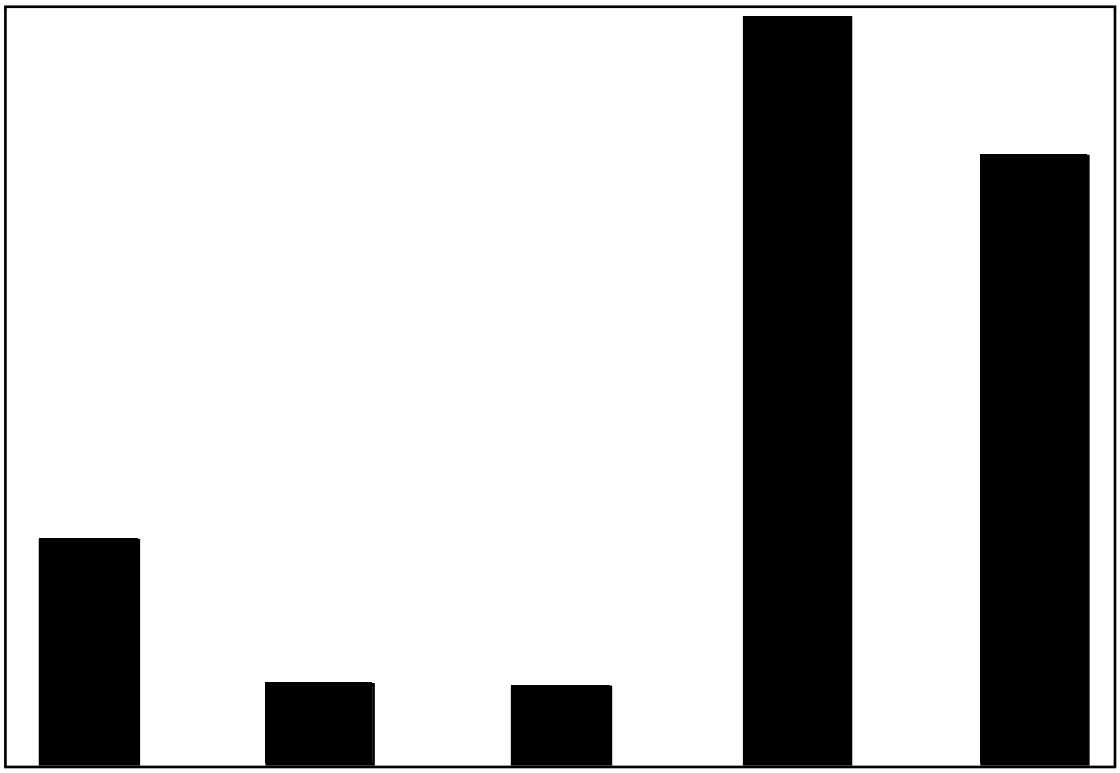

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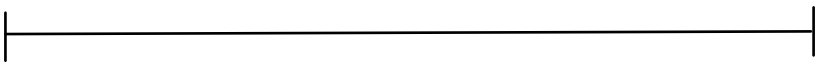

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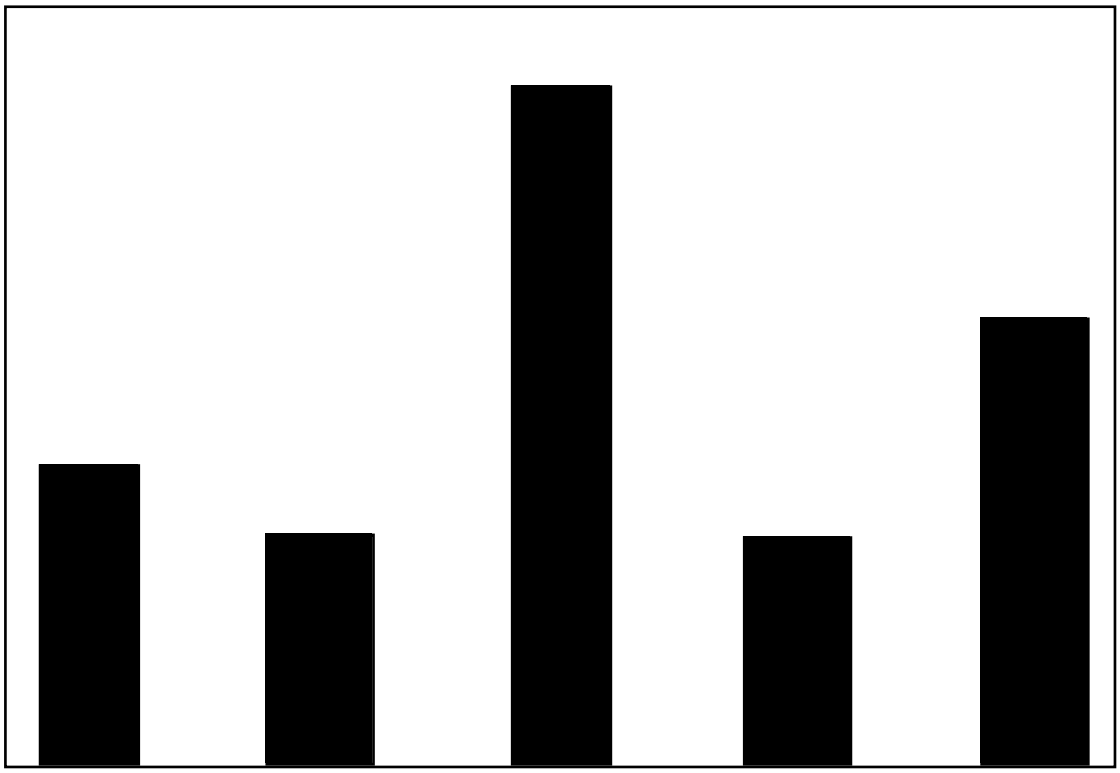

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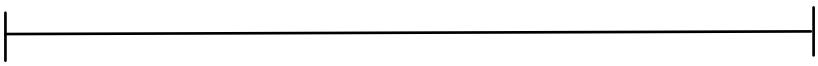

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