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HEDS Discussion Paper 06/08

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An Internet “Value of Health” Panel: recruitment, participation and compliance

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KEY WORDS

Utility; Internet; Public; Survey

RUNNING TITLE (40 characters)

VALUE OF HEALTH PANEL PILOT – RECRUITMENT

CONTRIBUTIONS

Ken Stein, Ruairidh Milne, John Brazier and Ali Round developed the idea of the Value of Health Panel and, with Julie Ratcliffe, designed the evaluation.

Matthew Dyer and Tania Crabb collected relevant data and assisted with statistical analysis as required during the project.

All authors contributed to the drafting of this document.

SUMMARY

OBJECTIVES

To recruit a panel of members of the public to provide preferences in response to the needs of economic evaluators over the course of a year

METHODS

A sample of members of the UK general public were recruited in a stratified random sample from the electoral roll and familiarised with the standard gamble method of preference elicitation using an internet based tool. Recruitment (proportion of people approached who were trained), participation (defined as the proportion of people trained who provided any preferences) and compliance (defined as the proportion of preference tasks which were completed) were described. The influence of covariates on these outcomes were investigated using univariate and multivariate analyses.

RESULTS

A panel of 112 people was recruited. The eventual panel reflected national demographics to some extent, but recruitment from areas of high socioeconomic deprivation and among ethnic minority communities was low. 23% of people who were approached (n= 5,320) responded to the invitation to take part in the study, and 24% of respondents (n=1,215) were willing to participate. However, eventual recruitment rates, following training, were low (2.1% of those approached), although significantly higher in Exeter than other cities. 18 sets of health state descriptions were presented to the panel over 14 months. 74% of panel members participated in at least one valuation task. Socioeconomic and marital status were significantly associated with participation. Compliance varied from 3% to 100%, with the average per set of health state descriptions being 41%. Compliance was higher in retired people but otherwise no significant predictors were identified.

CONCLUSIONS

It is feasible to recruit and train a panel of members of the general public to express preferences on a wide range of health states using the internet in response to the needs of analysts. In order to provide a sample which reflects the demographics of the general public, and capitalise on the increasing opportunities for the use of the internet in this field, over-sampling in areas of high socioeconomic deprivation and among ethnic minority communities is necessary.

INTRODUCTION

Although concerns have been expressed about the use of cost utility analyses (CUA)(1;2), the number of published such analyses has increased in the past ten years(3). Guidelines in the UK and Canada, and those proposed by the Washington Panel on cost effectiveness in the USA, promote CUA where the purpose of the analysis is informing public resource allocation.(4-6) The UK's National Institute for Health and Clinical Excellence (NICE), building on earlier regional work(7;8), has made cost utility an explicit aspect of policy making(6), though the precise level at which a QALY gained is considered to represent acceptable value for money has been the subject of debate.(9;10) The UK and Washington Panel reference cases suggest that the perspective for the valuation of benefits in CUA should be that of the general public(6;11). The arguments around adopting this perspective are beyond the scope of this article, but are rehearsed elsewhere.(12-21)

The NICE reference case specifies that a “*generic (non-disease-specific) instrument is required to quantify the effects of technologies in terms of HRQL for patients. The value of changes in patients' HRQL (that is, utilities) should be based on public preferences elicited using a choice-based method.*”(6) A wide range of approaches has been taken in obtaining utility values in health technology assessments carried out for NICE.(22) Although the widespread use of standard measures such as the EQ5D and SF6D(23) may address some of the inconsistency in utility assessment in economic evaluations, there are three main reasons why research into alternative approaches remains justified. Firstly, there is no comprehensive set of generic HRQL data for all diseases and at all severities. Secondly, specific adverse events of

treatment may not be captured. Thirdly, the EQ5D and, to some extent, SF6D, may not capture all the relevant domains of quality of life in specific conditions (e.g. sensory deprivation).(24;25)

Recognising the need to obtain utility estimates for specific health state descriptions in a range of diseases using timely and consistent methods, we have piloted an approach using a panel of members of the public. The panel's function is to provide, using the internet, in as short a timeframe as possible, utilities for a range of health states. Health state descriptions are prepared from condition specific quality of life measures, with face validation by clinical experts, and presented in bullet, rather narrative, format(26). In this paper we describe initial recruitment and participation of the panel and discuss the potential for extension of this approach.

METHODS

RECRUITMENT AND TRAINING

We recruited panel members from a convenience sample of UK cities: Exeter, Sheffield, Glasgow and Aberdeen. A random sample was chosen from the electoral rolls for these cities in January 2004, crudely stratified for socio-economic status using tertiles of the Index for Material Deprivation (IMD2000)(27). We assumed a 15-20% response rate to the invitation to attend panel training based on the authors' previous experience with preference elicitation studies using face to face interviews and aimed for an arbitrary target sample size for the panel of 100.

Participants were invited by letter to express interest in joining the panel, accompanied with a short questionnaire seeking reasons for non-participation. Positive respondents were then invited to a three hour training session in each of the cities involved. Panel members were recruited and trained in two tranches during summer and autumn 2004, involving eight training sessions.

Training sessions covered the following areas as background: research and policy making; role of modelling in estimating cost effectiveness; limitations of existing methods for utility assessment. Participants were familiarised with the standard gamble task, using formats appropriate to whether the health states were thought to be better or worse than death, with one-to-one support from facilitators.

Health state descriptions were placed on the website for at least three weeks.

Descriptions were posted in sets corresponding to different states within the same

condition (e.g. levels of severity or treatment side effects). Participants encouraged by email to provide preference values in this period. Panel members who valued any descriptions within the three week period were entered into a cash lottery for £50, held after each set of descriptions were taken off the internet site. A regular newsletter was sent to participants reporting participation.

Preference elicitation

Panel members were asked to consider themselves in the described health state, for a period of twenty years, or the rest of their life.(28) The standard gamble was used, based on the axiomatic advantage that it reflects choices made under conditions of uncertainty.(29) This was carried out using bottom-up “titration”, in which respondents work through choices with increasing probability of good outcome in the gamble option. We used this approach rather than “ping-ponging” between options with high and low probabilities of worst outcome in the gamble(30) in order to simplify the procedure for self-completion.

Internet Site Development

The website was created in 2004 and piloted by the project team and the first panel members. It includes the standard gamble interface, information on the project, and a bulletin board for sharing questions and information on the project.

The standard gamble interface (see Figure 1) has several features of interest:

- It is not possible for participants to enter responses which are fundamentally illogical e.g. preferring the gamble at a given probability of restoration of full

health, but then preferring the health state of interest when this probability increases.

- Participants who indicate that they would take the gamble where the probability of death is 1.0 must confirm that they consider the health state description worse than being dead. They are then automatically taken to an interface which presents the options appropriately for the elicitation of negative utility values.
- The changing probabilities in the gamble choice are represented graphically as a bag of different coloured balls, each representing the potential outcomes of full health and death.
- All choices must be made before the response will be accepted
- The increments for changing probability in the gamble are set at 1% between probabilities of full health of 0.95 and 1.0 in the gamble option.

Responses are downloaded into a database with a PERL script automatically calculating the respondent's utility for the health state description.

Analyses

The demographic characteristics of the panel are compared to data from the UK National Census carried out in 2001.

The panel's performance is described using three outcomes. Firstly, for each set of health state descriptions, the proportion of panel members who provided any responses is described – *participation by health state description set*. Secondly, *participation by panel member* is defined as the proportion of panel members who

carried out any valuation tasks during the study period. Thirdly, *compliance* is described for panel members who carried out at least one valuation task (participants) and defined as the proportion of health states valued.

Potential determinants of participation by panel member and compliance were explored through univariate and multivariate analyses using SPSS for windows version 11. Age, marital status, occupation and ethnicity were collected from panel members at recruitment. Socioeconomic status was attributed according to place of residence, using the Scottish Index of Material Deprivation (SIMD) for Aberdeen and Glasgow(31), calculated at postcode sector level and the 2004 version of the Index of Material Deprivation for Exeter and Sheffield at Lower Super Output Area (LSOA) level(32). LSOAs contain populations of 1000-1500 people. For the purposes of the analysis, SIMD and IMD were treated as a single scale. Other variables considered were city of residence, nationality (Scottish or English) and training session.

RESULTS

Recruitment and retention

Recruitment was carried out in two waves. Initially, people in Exeter, Sheffield and Aberdeen were recruited and trained. It became clear that the target panel size would not be met from this sample and a further round of recruitment took place in Exeter and Glasgow to increase panel size. Overall, recruitment and training took around seven months. The panel carried out valuation tasks from August 2004, although complete membership (n=112) was not achieved until November 2004.

5,320 people were contacted through the electoral roll, giving an overall initial participation of 2.1% of those approached. Only 1215 (23%) of those approached responded to the initial invitation letter. Of this group, 286 (23.6%) expressed willingness to participate in the project and 112 (39%) attended training sessions. Only people who attended a training session were included in the panel.

Recruitment was more successful in Exeter than the other cities (see Table 1: $\chi^2 = 41.18$, $P < 0.001$), as was reporting of reasons for declining the initial invitation (see Table 2: $\chi^2 = 12.86$, $P < 0.001$). Lack of time and internet access were the main reasons given for declining the initial invitation to participate. Internet access was better among respondents in Exeter and Aberdeen than Glasgow or Sheffield (see Table 2).

Panel Member Characteristics

The age range of panel members was 18 to 79 years with mean 48 years. The panel includes a higher proportion of people in middle age than the UK population as a whole, and fewer younger and older people (see Figure 2).

Table 3 shows the demographic characteristics of the panel members. There were more women ($n=58$) than men ($n=54$). Men were, on average, slightly older. Table 3 also shows that the panel had a higher proportion of married and retired people with correspondingly lower proportions of unmarried people those in employment than the national population. People from non-white ethnic backgrounds were particularly under-represented in the panel.

Table 4 shows the proportions of panel member from each city whose area of residence falls into each tertile of IMD or SIMD scores ranked at national level for Scotland or England. So, if the panel reflected the national distribution of socioeconomic status as measured by the IMD/SIMD, the samples from each city would contain 33% of people in each national tertile. People from areas of high deprivation are under-represented in the panel, particularly in Exeter and Sheffield. The numbers of people recruited from Scotland were low, making this comparison imprecise.

Participation and compliance

During the first year of the project (October 2004-5), 25 members of the panel formally withdrew. There was no statistical association between age, sex or socioeconomic status and explicit withdrawal from the project.

Eighteen sets of health state descriptions were presented to the panel between October 2004 and December 2005, depicting health states in 11 separate conditions. Three sets were presented twice to evaluate reliability and several generic health state descriptions based on the EQ5D were included for comparison with the values obtained by Dolan *et al*(33).

Across all the health state descriptions, 565 completed sets were provided i.e. values were given on all health state descriptions in the set. In only 13 (2.3%) were responses from a set received on more than one day, suggesting that panel members

provided values in one session. In cases where preferences within a set were expressed over more than one day, no more than two submission dates were shown. In these cases, the range between initial and final submissions was 1 to 28 days (mean 6.9 days, median 6 days).

Although health state descriptions were posted on the website for more than three weeks in some cases, panel members were asked to complete the sets within this time. Figure 3 shows the cumulative probability of obtaining values within that period.

Taking variations in panel membership into account, overall average participation by health state description set was 41% (range 24%-65%). Figure 4 shows participation for each set of descriptions over time. In 94.5% of cases where panellists considered at least one health state in a set, all states were valued.

Overall, 83 people (74.1%) participated in the project i.e. carried out at least one valuation. Univariate analysis showed no significant association with participation and age, sex, nationality, city, retirement status or training session. Data on ethnicity were incomplete and excluded from further analysis.

Socioeconomic status was significantly associated with participation (t test, $t=3.713$, $P=0.013$), as was marital status. 86% of married people participated versus 52.5% of unmarried people ($\chi^2=13.90$, $P<0.001$).

Logistic regression confirmed the independent effects of socioeconomic status and marital status on participation (see Table 5) with pseudo- R^2 for the model being 0.25.

Compliance ranged from 3-100% (see Figure 5). There was no association between compliance and age (Spearman correlation, $P=0.92$); sex (t test, $P=0.422$); nationality (ANOVA, $P=0.23$); city (ANOVA, $P=0.631$); marital status (t test, $P=0.568$); or IMD/SIMD score (Spearman correlation, $P=0.40$). However, mean compliance was associated with employment status, being higher among retired people (54%) and people in full time employment (52%), (see Table 6: $P=0.023$).

DISCUSSION

This is the first attempt, of which we are aware, to collect new utility data from members of the public for the specific purpose of informing ongoing cost utility analyses. The study is unusual in presenting different health state descriptions over a period of time. Although we have demonstrated feasibility, recruitment to the panel was very low. This was, in part, determined by the need for attendance at a training session. Initial positive response to the invitation to participate was similar to that shown in studies aiming to recruit for a single episode of health state valuation using face to face interviews.

Across health state description sets, participation was around 40%, giving a sample size range for each health state description of 28 to 62. Participation by health state description set declined during the study period, demonstrating the need for ongoing recruitment and training. However, around 30% of the panel remained compliant at one year. The role of the limited financial inducement offered to panel members is not clear. Further research is required on the impact of different approaches to

payment (e.g. lottery versus certain payment) and their impact on recruitment as well as participation and compliance.

The three week period chosen for valuation tasks was arbitrary but appears appropriate. The probability of completion by that time point was very high, even where health state descriptions were available on the website for longer. This issue has not been addressed in previous studies.

The demographic make up of this pilot panel does not reflect Scotland and England as a whole. This was not unexpected: one of the purposes of the pilot study was to understand better the determinants of recruitment, participation and compliance so as to inform the establishment of a larger, more representative panel. Representation of people from more deprived areas, and from ethnic minority groups, was particularly low, demonstrating the challenge for engagement which is shown in other types of study.⁽³⁴⁾ This was despite attempting to stratify the sample according to socioeconomic status. Utility values systematically vary according to age⁽³⁵⁾, gender and socioeconomic factors,⁽³⁶⁾ as well as previous experience of illness⁽³⁷⁾ and these factors might reasonably be considered important in establishing a panel. However, the importance of risk attitude as a factor in the external validity of preference studies is less well recognised. To our knowledge, no large scale studies of risk attitude exist for the UK population, on which judgements regarding the representativeness of utility studies using the standard gamble could be based.

In addition to the low initial recruitment from areas of higher socioeconomic deprivation, participation is also negatively associated with lower socioeconomic

status. The association between marital status and participation is not explained by covariance with the other limited independent variables. However, compliance was, surprisingly, not associated with socioeconomic status, suggesting either that the number of participants was insufficiently large to demonstrate an effect, or that the principal impact of socioeconomic status is on participation. Lack of adequate access to the internet or lack of effectiveness in training sessions would be consistent with the latter hypothesis. The association between participation and marital status was not shown for compliance. Indeed, compliance was associated only with employment status, with higher compliance among retired people and those in full time employment. Although the significant finding on ANOVA may be driven by the particularly low compliance, and very small sample, among unemployed people and students, it may also be due to greater time to comply with valuation tasks among retired people and more regular access to the internet among people in full time employment.

The use of computer-based preference elicitation is not new(38). Sumner *et al* developed the Utiter programme in 1991(39). This was followed by U-Maker(40), Gambler(41), iMPACT(42;43) and, more recently, ProSPEQT(44). In addition, bespoke computer based utility assessment has been used in a wide range of studies(45-47) and as a teaching tool(48). Computer based utility measurement has potential advantages over interviewer-based methods: lower cost once software has been developed; elimination of interviewer variation; avoidance of transcription errors in data entry; potential to address logical errors automatically(49); and increased flexibility over the time required to complete the task. Acceptability among members of the general public is reasonable, although the standard gamble has been rated as

less acceptable than visual analogue scaling or time trade off in one relevant study.(50)

The use of the internet is a logical extension to the development of computer-based utility measurement tools. The most technically sophisticated approach is iMPACT3, developed by Lenert and colleagues. This uses an object orientated approach to facilitate the depiction of health states using written descriptions or multi-media presentations(51) and includes automatic error correction.(52) Ubel and colleagues have also developed a series of internet-based tools, including the person trade off(53) for use in a range of experiments(54-57).

Although the NHS Value of Health Panel project shares many of the features of other internet based preference measurement systems, it is unique in having recruited and maintained a group of members of the public who have expressed preferences on a wide range of health state descriptions. Recruitment was, however, not internet-based. There are no published accounts of recruitment to preference studies using the internet, although Ubel and colleagues have reported obtaining a large representative sample of US citizens for one study.(55) The establishment of internet panels for market research has increased dramatically in the past five years. Harris Interactive, advertise a global panel of 1 million members, with 600,000 in the USA (<http://www.harrisinteractive.com/advantages/hpolpanel.asp>, accessed 30 December 2005). In the UK, YouGov has recruited a panel of 89,000 people through internet advertising and floated on the stock exchange in 2005(58). However, the representativeness of even such large internet panels remains a concern. Internet penetration in the UK is only around 52% and people who are likely to join internet

panels are more likely to be politically interested and knowledgeable than those less likely to participate.(59)

However, it seems likely that the upward trend in internet access will continue, as will access to broadband technology. This presents important opportunities for preference measurement and research with, potentially, advantages over one to one interviews. For example, large numbers of people can be involved; alternatives to written descriptions can be used; costs are likely to be less than one to one interviews; automatic checks for illogical responses can be integrated; and various approaches to representing risk (or time) in preference measurement can be explored. In short, the potential for using the internet in this field is only beginning to be exploited.

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Table 1: Recruitment by City

	Exeter	Sheffield	Glasgow	Aberdeen	All sites
	N (%)				
Sent invitation letter	1892	1892	1000	536	5320
Positive response to invitation letter	151 (8.0%)	84 (4.4%)	29 (2.9%)	22 (4.1%)	286 (5.4%)
Attended training i.e. joined panel	72 (3.8%)	22 (1.2%)	11 (1.1%)	7 (1.3%)	112 (2.1%)
Gave reasons for declining initial invitation	263 (13.9%)	210 (11.1%)	98 (9.8%)	55 (10.3%)	626 (11.8%)

Table 2: Reasons for declining initial invitation

City	Don't understand the project	Not interested	Don't have time	No access to the internet	Other	Total
	N (%)					
Exeter	7 (3)	7 (3)	101 (38)	49 (19)	99 (38)	263
Sheffield	8 (4)	7 (3)	70 (33)	100 (48)	25 (12)	210
Glasgow	0	4 (4)	30 (31)	51 (52)	13 (13)	98
Aberdeen	4 (7)	3 (5)	16 (29)	28 (51)	4 (7)	55
All cities	19 (3)	21 (3)	217 (35)	228 (36)	141 (23)	626

Table 3: Panel member personal characteristics

	Panel Characteristics						National (England and Scotland)	Difference between Panel (total) and National
	Males		Females		Total			
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>		
Age	50.5	13.4	46.0	13.0	48.2	13.3		
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>%</i>	<i>% (P)</i>
Employment								
Student	2	3.7	5	8.6	7	6.3	8.2	-1.9 (NS)
Full-time	25	46.3	22	37.9	47	42.0	55.7	-13.7 (0.003)
Part-time	2	3.7	13	22.4	15	13.4	16.0	-2.6 (NS)
Unemployed	0	0	3	5.2	3	2.7	4.0	-1.3 (NS)
Retired	14	25.9	7	12.1	21	18.8	16.0	2.8 (NS)
Other	5	9.3	5	8.6	10	8.9		
Unknown	6	11.1	3	5.2	9	8.0		
Marital Status								
Married	33	61.1	37	63.8	70	62.5	40.6	21.9 (<0.0001)
Single	11	20.4	10	17.2	21	18.8	44.5	-25.7 (<0.0001)
Divorced	3	5.6	5	8.6	8	7.1	6.3	0.8 (NS)
Separated	1	1.9	1	1.7	2	1.8	2.0	-0.2 (NS)
Widow	1	1.9	1	1.7	2	1.8	6.6	-4.8 (0.039)
Unknown	5	9.3	4	6.9	9	8.0		
Ethnicity								
White	44	81.5	42	72.4	86	76.8	91.4	-14.6 (0.013)
Non-white	0	0.0	1	1.7	1	0.9	8.6	-7.7 (0.013)
Unknown	10	18.5	15	25.9	25	22.3		

Table 4: Panel compared to national distribution of socioeconomic status

	N (%) Panel members whose residence falls into national tertiles of IMD* or SIMD*		
City	High	Medium	Low
Exeter	12 (16.2)	26 (35.1)	34 (45.9)
Sheffield	4 (18.2)	7 (31.8)	11 (50.0)
Glasgow	7 (63.6)	3 (27.3)	1 (9.1)
Aberdeen	2 (28.6)	0	5 (71.4)
Total	25 (22.3)	36 (32.1)	51 (45.5)

High = most socioeconomic deprivation

Low = least socioeconomic deprivation

Table 5: Logistic regression of marital status and IMD/SIMD on participation

	Beta	S.E.	Sig.	Odds Ratio
Marital status	1.444	0.512	0.005	4.237
IMD/SIMD score	-0.043	0.020	0.029	0.958
Constant	1.057	0.566	0.062	2.877

Table 6: Compliance by employment status

	N	Mean % compliance	95% Confidence Interval for Mean	
			Lower Bound	Upper Bound
Student	4	35.6	0	82.0
Full time employment	33	51.7	40.9	62.4
Part time employment	13	32.9	19.2	46.6
Unemployed	2	10.4	0	82.3
Retired	16	53.9	34.8	72.9
Other	8	20.3	1.8	38.8
Total	76	43.7	36.6	50.8

ANOVA: F=2.792, P=0.023

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Figure 3: Probability of participation (by health state description set) within 21 days

Figure 4: Participation over time

Figure 5: Distribution of compliance

Figure 1: Standard Gamble Interface

Scenario VP/15 8/087 MATHS to concrete for inpatients

How does your sleep?

- It usually takes you between 30 and 60 minutes to fall asleep at night but often you lie awake for less than 30 minutes.
- Sometimes you sleep for 3 - 4 hours a night.
- Less than once a week your sleep is disturbed and you wake up at night.
- We have to take medication less than once a week to help you sleep.
- During the day you sometimes lack energy and enthusiasm to get things done and less than once a week you have difficulty staying awake when driving, eating or socialising.

A: Certain Outcome

You will stay in this health state for 30 years (or the rest of your natural life) and then die.

A - Stay as you are

B: Uncertain Outcome

You might be restored to full health immediately, and stay that way for 30 years (or the rest of your natural life).

OR - You might die immediately.

If you choose choice B you have:
80% chance of full health. Or 20% chance of death.

B - Take the chance



Imagine a bag with red & green balls. Choice A is the taking out one red without looking. We take 1 or immediately green ball = full health.

U - Too difficult to choose

Please enter your choice from the options above

Your Responses

◀ Previous Submit Your Responses Next ▶

chance of full health	0%	1%	2%	3%	4%	5%	6%	7%	8%	9%	10%	11%	12%	13%	14%	15%	16%	17%	18%	19%	20%	21%	22%	23%	24%	25%	26%	27%	28%	29%	30%		
chance of death	100%	99%	98%	97%	96%	95%	94%	93%	92%	91%	90%	89%	88%	87%	86%	85%	84%	83%	82%	81%	80%	79%	78%	77%	76%	75%	74%	73%	72%	71%	70%		
your response	A	A	A	A	A	A	A	A	A	A	U	U	U	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B

Figure 2: Value of Health Panel age structure vs UK population

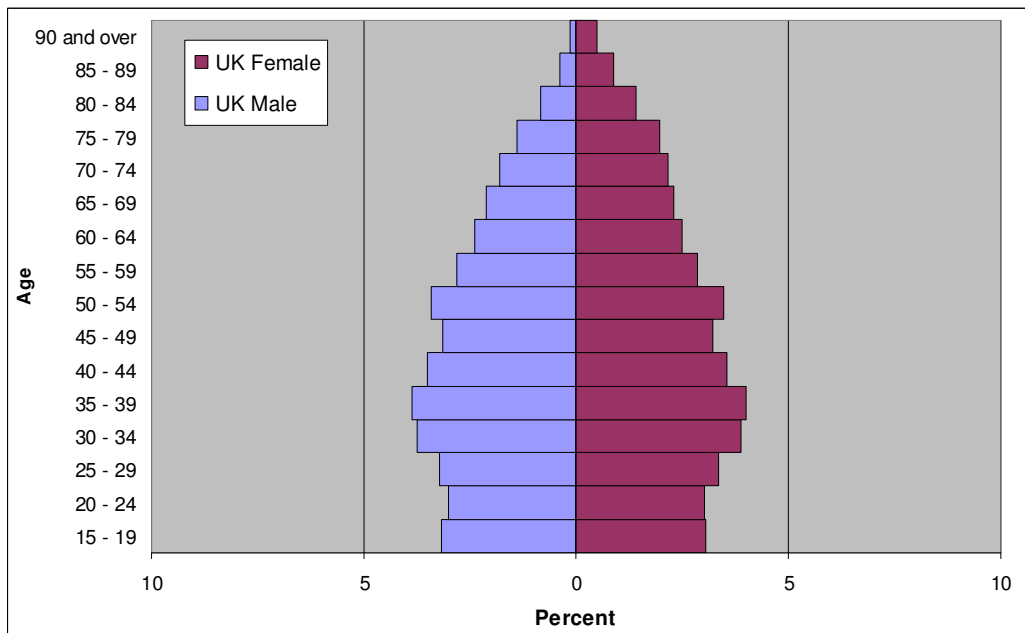
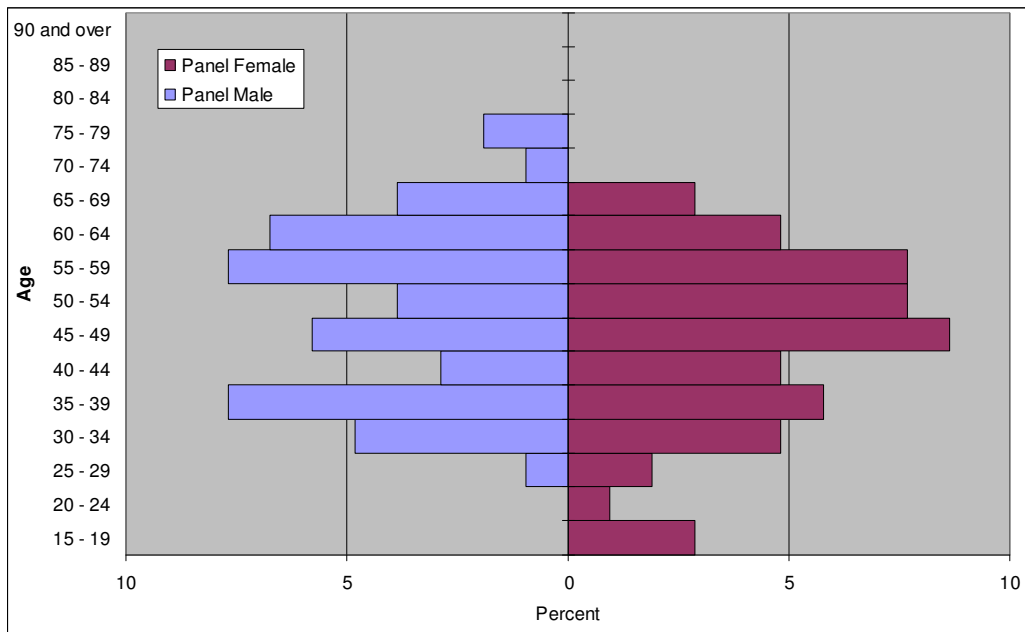


Figure 3: Probability of participation (by health state description set) within 21 days

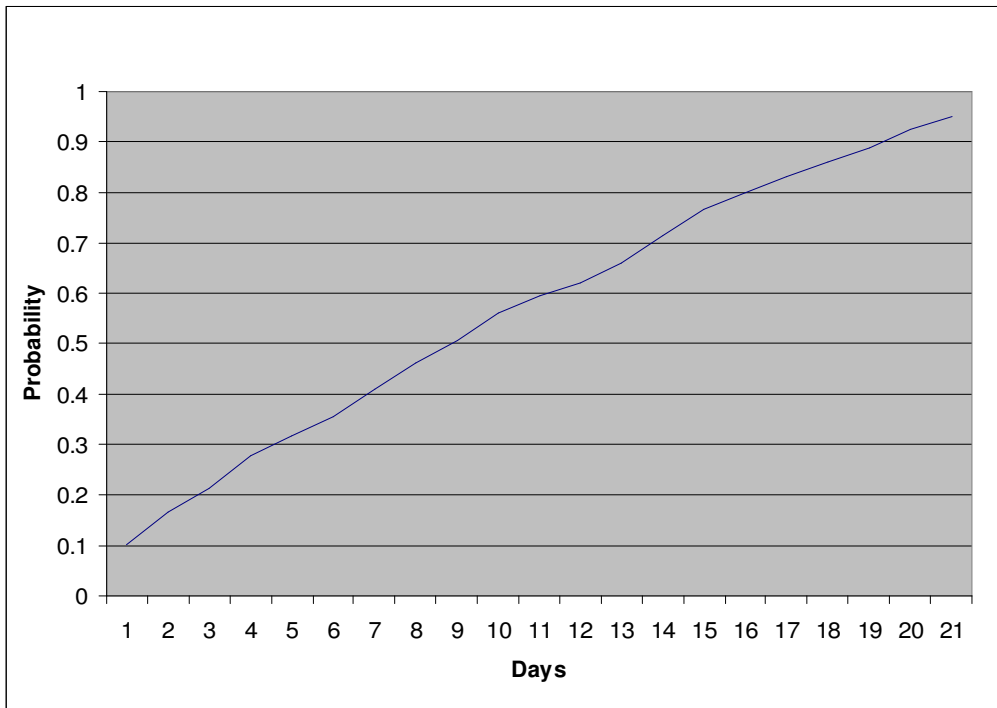


Figure 4: Participation over time

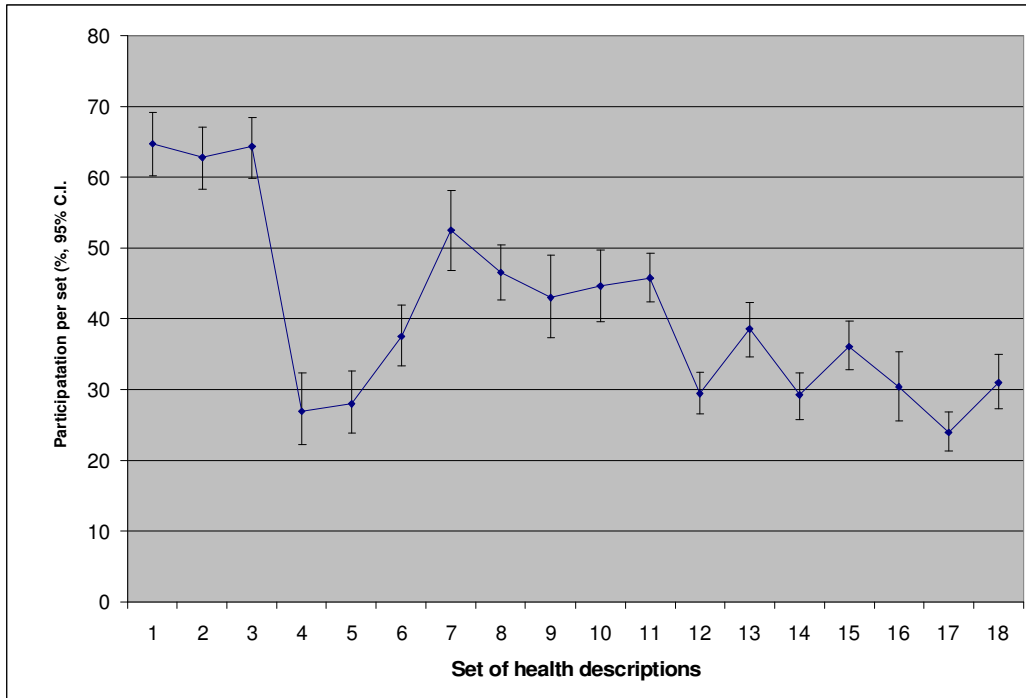
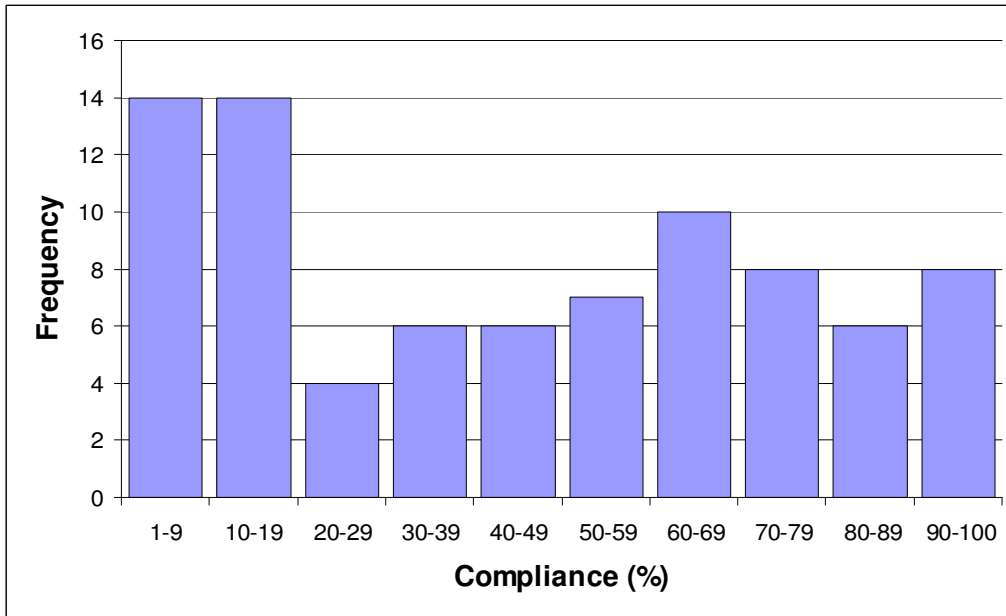


Figure 5: Distribution of compliance



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