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Development of a tool for the evaluation of public & patient involvement in research

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Abstract

Objectives: Public and patient involvement (PPI) is required at all stages of research by many funding bodies such as the NIHR. Given the high priority of PPI within NIHR research programmes and the associated costs it is important that the process of involvement and impact of PPI on health services research is evaluated. We aimed to develop a tool to quantitatively evaluate the quality of PPI in research from a PPI participant's perspective in order to inform the researchers about absolute level of quality (cross-sectional aspect) and changes in quality over time (longitudinal aspect).

Setting: A primary care patient safety translational research centre.

Participants: The 12 members of the research user group (RUG) of Greater Manchester Primary Care Patient Safety Translational Research Centre.

Interventions: By their own choice each RUG member supported a specific research theme. The level of involvement varied from commenting on documents through to designing their own research projects.

Primary and secondary outcome measures planned:

- Measure absolute score and change in score over time in a 9 point Likert score within individuals.
- Compare Likert scores before undertaking PPI with scores after PPI activities.
- Evaluate the usefulness of a questionnaire based on a theoretical framework of personal and research factors.

Results The questionnaire had an acceptable to good level of internal consistency (Cronbach's alpha 0.74 – 0.81). The majority of the individuals met their initial expectations (11/12) and scored high across all factors. There was no significant change over time in the aggregate score over all factors and all individuals but there were differences within individuals and factors. A ceiling effect limited the questionnaire's usefulness to measure increasing scores.

Conclusions The questionnaire has been useful in evaluating the early stages of a PPI group and may be generalizable to another setting.

Article summary

Strengths of this study

- We have designed and used a questionnaire based on a framework for quality in PPI that can be used to quantitatively evaluate PPI in research for the first time.
- The questionnaire showed good internal consistency between factors identified in a theoretical framework and was discriminatory in identifying individuals with decreasing satisfaction.
- The questionnaire simultaneously addressed both absolute opinions and changes over time avoiding bias potentially arising when using relative measures.
- Using a within subject random effects regression analysis allows an estimate of overall change in score allowing monitoring of overall PPI quality even though individual PPI participants may change.

Limitations of this study

- A ceiling effect made the questionnaire less useful for measuring increasing scores.

Background

The National Institute for Health Research (NIHR) research programmes require active involvement of patients and the public (PPI) at all stages of research, for example in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.[1] In the same way that the public have a right to have a say about services that are provided for them, they also have an ethical right to oversee and influence the direction taken by research into healthcare provision.[2,3] The Greater Manchester Primary Care Patient Safety Translational Research Centre (Greater Manchester PSTRC) is an NIHR funded Research Centre addressing patient safety in primary care settings.[4] Within the Greater Manchester PSTRC, after an open public call for recruitment, a Research User Group (RUG) was established in September 2013 to fulfil both a strategic governance role and contribute PPI to research activities. Given the high priority of PPI within Greater Manchester PSTRC and NIHR research programmes it is important that the process of engagement and impact of PPI on health services research is evaluated. Although researchers, members of the public and policy makers believe that it is possible to evaluate the impact of PPI on research it rarely happens.[5]

An individual has many personal reasons for being involved in PPI and these can be encouraged or discouraged by the structures or processes of research and/or the relationships with the researchers. A published theoretical framework aiming to assess the quality of PPI in a research context identified the underlying concepts or factors outlined in box 1.[6] We aim to develop and apply a questionnaire based on this framework to quantitatively evaluate the quality of the PPI within the RUG that may be generalised to other settings. The questionnaire aims to address the questions below.

1. Have the *a priori* expectations of the PPI participants been met?
2. How well is PPI functioning in terms of personal and research factors?
3. Is the quality of the PPI changing over time?
4. Are the scores for personal factors correlated with those for research factors?

Furthermore we would like to develop a short version of the full questionnaire to avoid over-burdening of respondents in future.

Box 1. Quality involvement framework factors in evaluating the quality of PPI in research [6]

Personal factors

1. Being valued *e.g.* being paid and treated hospitably
2. Achieving one's own goals through involvement
3. Feeling able to make a contribution (empowered)

Research factors (relationships and ability to participate)

4a. A clear role for PPI in research and supportive structures e.g. motivated researchers, adequate funding and access to guidance on the processes of research

4b. Support at the organisational level and by existing ethical and governance systems

5. Application of previous experience as a service user or supporting research

Methods

The RUG consists of 12 members with an elected chair that met every 4-6 weeks between Sept13 and Apr14 (6 times in total). RUG members each support a specific research theme (by their own choice from medication safety , multimorbidity, general practice, interface and informatics) or the core theme which focuses on administration and PPI. Expenses are paid at the INVOLVE rate which

depends on the individual circumstances and the nature of the task (e.g. the daily committee fee is £150).[7] RUG members may be involved at all levels and stages of research from commenting on documents to designing their own projects.

The questionnaire [6] was adapted to the specific context of the Greater Manchester PSTRC and a further question assessed whether or not the PPI group (RUG) followed the ground rules that they developed among themselves (Appendix 1). Whether or not the RUG members met their own expectations was assessed by comparing an expectations questionnaire with the evaluation questionnaire. The expectations questionnaire consisted of twelve questions adapted from the evaluation questionnaire by replacing "Are you able to…" with "Do you expect to be able to…" etc (denoted E in Appendix 1). The expectations questionnaire was completed before the first RUG meeting and the evaluation questionnaire was completed on-line within 1 week of each RUG meeting. The question order was randomised for each individual and each administration.

Responses were measured on a 9 point Likert scale. The internal consistency of the responses within each factor on the first administration was estimated by Cronbach's alpha. For each participant the mean response score for each factor (1-5, Box 1) over all 6 surveys was used to indicate the overall response score and a linear regression analysis provided an estimate of the change in score over time. The response score was the dependent variable and survey number and question number were categorical predictors. In order to provide a score representing the whole group the mean score per factor was measured and the change in score over time was estimated using a 2 level linear regression model in Stata (xtreg). The dependent variable was the response score nested within individuals (the random effects or higher level in the model). The main predictor was survey number and question number was included as a categorical independent variable. The results are presented as the change in response score (assuming a linear trend) over the 6 surveys for each factor and across all factors. The question about adherence to the RUG ground rules (Q22) was a single item Likert-type scale therefore a non-parametric approach was taken (Kendall tau rank correlation coefficient).[8] A paired T test was used to make comparisons between the scores in the expectations questionnaire and the mean score across all the surveys by question. Linear regression was used to compare the mean scores for personal factors and research factors. The use of regression models to analyse Likert scale data remains a long standing debate. [9] Arguably this data might be less likely to violate the assumptions of a linear regression in that it is truly Likert scale data as it uses several questions to address the same underlying concept and the wider 9 point scale was used. However the analysis was repeated using an ordered logistic regression model (ologit in Stata) to check that the assumptions made by the linear regression did not substantially alter the results. The advantage of the linear regression is the capacity to include random effects, *i.e.* to allow each individual to vary independently. An interim analysis was undertaken after 3 administrations of the questionnaire and feedback was provided to the researchers and the RUG.

For situations where a less detailed questionnaire is required the most representative or generalizable questions are for each factor were identified based on having the least number of "not applicable" responses and the lowest variance.

This paper was circulated amongst the RUG and their comments are considered in the discussion.

Results

The expectations questionnaire was completed by 11/12 (92%) RUG members and the survey completed 61 times out of 65 potential completions (94%). RUG members had high *a priori* expectations (mean overall score 7.2/9, Table 1) and these expectations were largely met (mean score over all members and all surveys 7.3/9, table 1). However one individual's experience (7.1/9)

did not meet their initial expectations (8.2/9, P=0.02; individual 5,Table 1); this member subsequently resigned.

The questionnaire performed well across all factors with an acceptable to good level of internal consistency within each factor 1-5 (Cronbach's alpha 0.74 – 0.81) for survey 1. Out of 1159 potential responses to questions 1-19, 86 (7%) were answered "not applicable", these were distributed equally across the questions and omitted from the analysis. There was a significant correlation between the mean scores for personal and research factors (P<0.001, R^2=0.93). Just one RUG member expressed difficulty in understanding the meaning of questions 3, 7, 11, 12 and 20.

The whole group score over all factors was high (7.3 ±0.04, Table 2) and over all RUG members and factors there was no significant change in score (-0.01, -0.06, 0.05; Table 2). The estimated change in individual scores and across the whole group is shown in Fig 1. At the individual level there were 3 individuals showing an overall decreasing trend and one with an increasing trend (3,9,11,6, Table 2).

Scores were high for both personal and research factors over the whole group (7.0 – 7.8, Table 2) and factors 2-5 (achieving own goals, empowered, sufficient research support and relevance of previous experience) showed no significant change in score over time (Fig 2). However within factor 1 (being valued) the small decrease in score across the whole group approached significance (-0.08; -0.16, 0.00, Table 2 & Fig 2). This was driven by 3 individuals with a small but significant decline in their scores (1,3,9, Table 2). One individual reported a significant decrease in their ability to achieve their own goals (10, Table 2). Another individual reported a significant decrease in feeling empowered (4, Table 2) but two reported a significant increase in empowerment (6,7, Table 2). One individual reported a decline in research factors (3, Table 2) and 2 individuals reported a decline in their belief that their previous experience was helpful (3,11, Table 2). Examples of the raw scores and the associated change estimated by the 2 level regression model are shown in Table 3 to assist with interpretation. The RUG followed its own ground rules and this remained stable across all the surveys.

Three members of the RUG resigned during the survey period. One individual only completed the questionnaire twice and gave low scores (8, Table 2). Another resigning member scored showed no change in score (+0.12, -0.06, 0.29; 5, Table 2) although their expectations score was higher than their mean survey score (5, Table 1). A third resigning member showed decreasing satisfaction over time (-0.14, -0.26, -0.02; 11, Table 2). The other two individuals showing a pattern of significantly decreasing scores resigned within 3 months of the survey period (3,9, Table 2). All cited practical reasons for their resignation such as re-location or other time-consuming commitments.

Repeating the analysis using an ordered logistic regression model did not alter the interpretation of the results. The questions suggested for a short version of the questionnaire are denoted "S" in Appendix 1.

Discussion

The two main aims of this survey were to apply the questions and theoretical framework recommended by Morrow et al [6] and to evaluate the PPI in Greater Manchester PSTRC from the participant's perspective. With respect to the first aim the high response rate suggested acceptability of the questionnaire and Cronbach's alpha showed acceptable to good internal consistency suggesting reliability within the factors. The statistical method allows us to view the change in scores over time adjusted for the differences in individual absolute scores. We were able to identify a single question representing each factor based on minimising the variability between subjects (denoted "S" in Appendix 1). While we do not argue that this justifies replacing the longer

version, which is more statistically robust, it offers a compromise where it may be impractical to use the longer questionnaire.

With respect to the second aim the RUG had high expectations of the PPI which were largely met and overall scores representing levels of feeling valued, achieving one's own goals and empowered were high, as were the overall scores representing the quality of the relationships with the researchers and opportunities to participate. RUG members found their previous experience less helpful than they had initially anticipated but this varied widely over time (Fig 2). The small but significant decline in feeling valued (factor 1) over time needs to be addressed. The high scores created a ceiling effect thereby reducing the potential to measure increasing scores. For example in Table 3 it is clear that one individual could not record increased empowerment as they were already giving the maximum score of 9,9,9. This is always a potential problem when using a finite scale aiming to simultaneously measure absolute and change in score. In future versions of the questionnaire alternative versions of the scale labels could be tried [9] or the Likert scale replaced with a visual analogue scale. However maintaining high scores could be considered positive given that enthusiasm for most activities will naturally wane over time. It is arguable whether or not high expectations should have been encouraged at recruitment as this might lead to unrealistic expectations of the influence of the group.

The correlation between scores for personal and research factors is consistent with the hypothesis that higher levels of participation in research will lead to higher personal satisfaction but does not provide evidence for a causal relationship. It could equally be argued that individuals with higher levels of personal satisfaction are more likely to look for, or be open to, research opportunities.

The evaluation was intended to highlight any problems at an early stage so that appropriate action could be taken. A preliminary analysis after the 3rd survey suggested that some participants desired more research opportunities. As a consequence more involvement opportunities were offered at theme / project level. This coincided with a small overall increase in scores between survey 3 and 4. However it is possible that this led to members feeling overburdened leading to a small decrease in scores between survey 4 and 5.

An important question is whether or not a decrease in scores was observed leading up to the resignation of some RUG members. With hindsight there were some indicators of dissatisfaction leading up to resignations that occurred during the survey period; one individual failed to meet their expectations score, another had low scores right from the start and one showed an overall decrease in score. The other two individuals showing a pattern of decreasing scores resigned within 3 months of the survey period. RUG members showing similar patterns should receive extra support in future. However while the questionnaire may be able to retrospectively identify changes in scores it is less suited to an alert function; at least 3-6 months of data is required to identify a significant change in score.

In the discussions with the RUG following distribution of this paper some valuable insights were gained. One point was that the high response rate might be explained by a sense of obligation due to payment of expenses and it should not be assumed to mean that the questionnaire was acceptable. Another point raised was that they were not involved in deciding the questions so the questionnaire may not reflect what they believe to be important. One aim of the questionnaire was to provide an objective evaluation based on generalisable concepts rather than the opinions of this specific PPI group but also there was a practical reason in that the expectations questionnaire had to be designed before the 1st RUG meeting. One constructive suggestion was that a question be added addressing whether the level of involvement is burdensome, too little or about right.

Although this analysis focuses on quality from the perspective of individuals participating in PPI, analysis is underway to set it within the context of quality in terms of impact and the researcher's perspective. Further work to explore whether the RUG had the factors identified in the theoretical framework in mind when completing the questionnaire is required to provide evidence of face validity for the questionnaire. Future work should address the ceiling effect [10] and other modifications that will make the questionnaire more responsive so that it can identify individuals who may benefit from extra support in a more timely fashion.

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Ethical approval: University of Manchester Ethics Committee Approval 13172

Data sharing statement: Raw data (numerical only) is available from jill.stocks@manchester.ac.uk

Contributorship:
SJS designed, administered and analysed the questionnaire and wrote the manuscript
SG identified the theoretical framework, designed the questionnaire, wrote the ethics application and commented on the manuscript
SG, SCS assisted with study design and commented on the manuscript.

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Figure legends

Fig 1. Changes in Likert score over time within individuals and over all individuals.

Fig 2. Changes in Likert score over time within factors and over all individuals.

Table 1. Comparison of mean expectations and evaluation survey scores.

ID	No of surveys	Mean score expectations ± SD	Mean score surveys 1-6 ± SD	P value Paired T test (by question)
1	5	7.6 ±0.33	8.0 ±0.13	0.28
2	6	6.4 ±0.47	6.1 ±0.20	0.67
3	6	6.9 ±0.38	7.4 ±0.11	0.24
4	6	8.3 ±0.47	7.7 ±0.15	0.32
5*	5	8.2 ±0.41	7.1 ±0.18	**0.02**
6	6	6.8 ±0.69	7.6 ±0.17	0.35
7	6	6.1 ±0.87	7.6 ±0.13	0.15
8*	2	6.2 ±0.55	5.1 ±0.37	0.15
10	6	7.2 ±0.37	7.0 ±0.16	0.63
11*	4	8.6 ±0.31	8.4 ±0.07	0.48
12	5	6.9 ±0.60	7.7 ±0.18	0.16
All	6	7.2 ±0.17	7.3 ±0.06	0.97

*Members who resigned from the RUG during the analysis period

Table 2. Mean scores and change in score over all evaluation surveys (1-6) within individuals and across the group

ID	No of surveys	Being valued (Q1-6)		Achieving own goals (Q7-9)		Empowered (Q10-12)		Research relationships & level of participation (Q13-19)		Experience as a service user or supporting research (Q20-21)		All factors (Q1-19)		Follow ground rules (Q22)	
		Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Median range	Tau-b P value
1	5	8.2 ±0.16	**-0.22 -0.38, -0.05**	8.4 ±0.25	-0.02 -0.31, 0.28	8.1 ±0.25	+0.12 -0.22, 0.46	7.8 ±0.18	-0.03 -0.21, 0.14	9.0 ±0.00	-	8.1 ±0.10	-0.07 -0.17, 0.04	7 4-8	0.55 0.47
2	6	5.2 ±0.29	+0.01 -0.37, 0.39	6.2 ±0.36	+0.34 -0.11, 0.79	6.4 ±0.47	+0.29 -0.03, 0.60	6.3 ±0.25	-0.07 -0.27, 0.14	8.2 ±0.47	+0.17 -0.40, 0.75	6.0 ±0.16	+0.09 -0.07, 0.24	7 6-7	-
3	6	7.3 ±0.17	**-0.31 -0.49, -0.12**	7.1 ±0.22	-0.14 -0.40, 0.11	7.3 ±0.24	-0.13 -0.34, 0.07	7.5 ±0.14	**-0.22 -0.36, -0.09**	7.3 ±0.21	**-0.35 -0.52, -0.19**	7.3 ±0.09	**-0.22 -0.31, -0.13**	8.5 7-9	0.23 0.68
4	6	6.9 ±0.20	-0.06 -0.32, 0.19	7.9 ±0.30	-0.23 -0.48, 0.02	7.8 ±0.37	**-0.47 -0.80,-0.13**	7.7 ±0.23	-0.09 -0.26, 0.08	9.0 ±0.00	-	7.5 ±0.14	-0.17 -0.29, -0.05	7.5 7-8	0.77 0.08
5*	5	6.7 ±0.29	-0.03 -0.44, 0.39	7.2 ±0.31	+0.03 -0.34, 0.41	7.1 ±0.28	+0.17 -0.17, 0.51	7.1 ±0.24	+0.25 -0.04, 0.54	5.8 ±0.36	+0.20 -0.44, 0.84	7.0 ±0.14	+0.12 -0.06, 0.29	7 7-8	0.26 0.77
6	6	7.5 ±0.24	+0.17 -0.10, 0.45	7.4 ±0.33	+0.02 -0.34, 0.37	8.4 ±0.23	**+0.28 0.04, 0.51**	7.6 ±0.24	+0.19 -0.02, 0.40	7.2 ±0.77	+0.06 -1.00, 1.12	7.7 ±0.13	**+0.17 0.04, 0.30**	9 8-9	0.18 0.82
7	6	7.5 ±0.17	+0.06 -0.13, 0.25	7.2 ±0.32	-0.04 -0.28, 0.21	7.4 ±0.33	**+0.28 -0.03, 0.53**	7.7 ±0.17	+0.02 -0.13, 0.16	6.8 ±0.46	-0.06 -0.62, 0.50	7.5 ±0.11	+0.06 -0.03, 0.16	8 8-9	0.00 0.38
8*	2	4.2 ±0.47	-0.75 -5.50, 4.40	4.3 ±0.49	+1.33 -0.10, 2.77	5.4 ±0.93	+0.50 -5.85, 6.85	5.4 ±0.49	0.00 -0.92, 0.92	8.5 ±0.29	-	4.9 ±0.29	+0.13 -0.76, 1.01	5.5 5-6	-
9	4	5.8 ±0.51	**-0.63 -1.22, -0.03**	6.2 ±0.59	-0.48 -1.31, 0.36	6.5 ±0.56	-0.23 -0.83, 0.38	6.5 ±0.42	-0.20 -0.55, 0.15	8.9 ±0.14	-0.12 -0.34, 0.10	6.3 ±0.25	**-0.38 -0.62, -0.13**	8 6-9	0.55 0.47
10	6	6.8 ±0.26	-0.04 -0.38, 0.30	6.4 ±0.23	**-0.31 -0.59, -0.03**	7.0 ±0.38	-0.06 -0.37, 0.25	7.2 ±0.19	0.00 -0.15, 0.16	8.8 ±0.18	-0.13 -0.35, 0.09	7.0 ±0.13	-0.06 -0.18, 0.06	7 6-7	0.63 0.29
11*	4	8.4 ±0.11	-0.06 -0.26, 0.14	8.3 ±0.13	-0.03 -0.35, 0.28	8.5 ±0.16	-0.18 -0.48, 0.12	8.5 ±0.14	-0.24 -0.48, 0.00	8.7 ±0.18	**-0.29 -0.63, -0.05**	8.4 ±0.07	**-0.14 -0.26, -0.02**	9 9-9	-
12	5	7.5 ±0.16	-0.06 -0.21, 0.09	6.9 ±0.57	+0.10 -0.22, 0.42	7.8 ±0.30	+0.03 -0.19, 0.26	8.1 ±0.13	-0.07 -0.19, 0.05	6.50. ±0.27	+0.06 -0.32, 0.44	7.7 ±0.13	-0.02 -0.11, 0.06	9 9-9	-
All	61/65 (94%)	7.0 ±0.09	-0.08 -0.16, 0.00	7.1 ±0.12	-0.02 -0.14, 0.10	7.4 ±0.11	+0.02 -0.07, 0.12	7.4 ±0.07	-0.02 -0.09, 0.04	7.8 ±0.15	-0.03 -0.17, 0.11	7.3 ±0.04	-0.01 -0.06, 0.05	8 4-9	0.13 0.24

*Resigned

Table 3. Examples of raw scores and resulting change in score estimated by linear regression

Mean change 95% CI	Change in factor 3 (Empowered)	Survey number					
		1	2	3	4	5	6
-0.47 (-0.80, -0.13)	Sig ↓	8,9,9	8,9,9	6,8,9	7,9,9	7,8,9	3,6,8
+0.28 (0.04, 0.51)	Sig ↑	6,8,9	8,8,9	7,8,9	8,9,9	9,9,9	9,9,9
-0.06 (-0.37, 0.25)	No change	m,7,9	5,7,9	m,7,8	6,6,8	3,7,8	7,7,8

Appendix 1

List of questions – all responses were on a 9 point Likert scale with a free text option. Questions marked S showed the least variation in response between individuals and are currently being used in a short version of the questionnaire. E indicates used in the expectations questionnaire.

Factor 1 -

1ES. Are you able to access GM PSTRC resources (e.g. expenses, facilities, information)?
2E. Are you able to make a contribution to the research within the GM PSTRC?
3E. Are you able to discuss research within the GM PSTRC?
4E. Are you able to influence decisions about how to do the research within the GM PSTRC?
(This is in a very general sense and might include methodology, timescales, research proposals, recruitment but other decisions should be considered too.)
5E. Are you able to express your views about research projects within the GM PSTRC?
6E. Are you able to take on new research challenges within the GM PSTRC?

Factor 2 -

7E. Is there potential for you to choose the type of role you play in the GM PSTRC RUG?
8ES. Is there potential for you to bring your own ideas and values to the GM PSTRC?
9E. Is there potential for you to gain status, expertise or credibility because of your involvement in the GM PSTRC RUG?

Factor 3

10S. To what extent do you feel valued as a partner within the GM PSTRC?
11. To what extent do you feel you are able to make an impact on the research undertaken by the GM PSTRC (i.e. how empowered or effective do you feel)?
12E. Is it acceptable that different people have different responsibilities and decisions to make about the research within the GM PSTRC?

Research context 4a

13. To what extent do you think the researchers in the GM PSTRC have the right reasons for wanting to work with you?
14E. Do you think the payment for your involvement in the GM PSTRC RUG is sufficient?
15. Do you have enough information about the research that is undertaken in the GM PSTRC?
16S. Are the staff within the GM PSTRC supportive?

Research context 4b

17E. Are the skills/experience needed for the GM PSTRC RUG clear to you?
18E. Are you aware of the legal and ethical guidelines for research (e.g. confidentiality)?
19. Do you feel your involvement is valued by the GM PSTRC partners? e.g. Salford Royal NHS Foundation Trust/University of Manchester/Clinical Commissioning Groups (CCGs) as well as by the GM PSTRC?

Research context 5 – value of previous experience as healthcare user or supporting research

20. Is your involvement in the GM PSTRC RUG helped because of any previous experience you have had as a healthcare user either personally or through relatives/ friends/ colleagues etc
21. Is your involvement in the GM PSTRC RUG helped because of any previous experience you have of supporting research studies?
(This refers to any research experience e.g. as a participant in a trial or through patient public engagement activities)

Additional question

22. How well does the GM PSTRC RUG follow its ground rules?

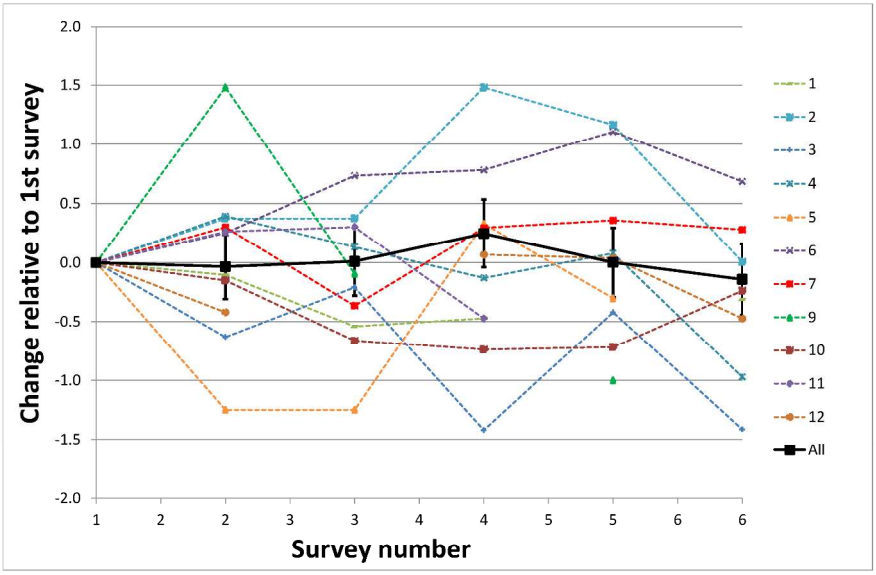

Fig 1. Changes in Likert score over time within individuals and over all individuals.
296x209mm (300 x 300 DPI)

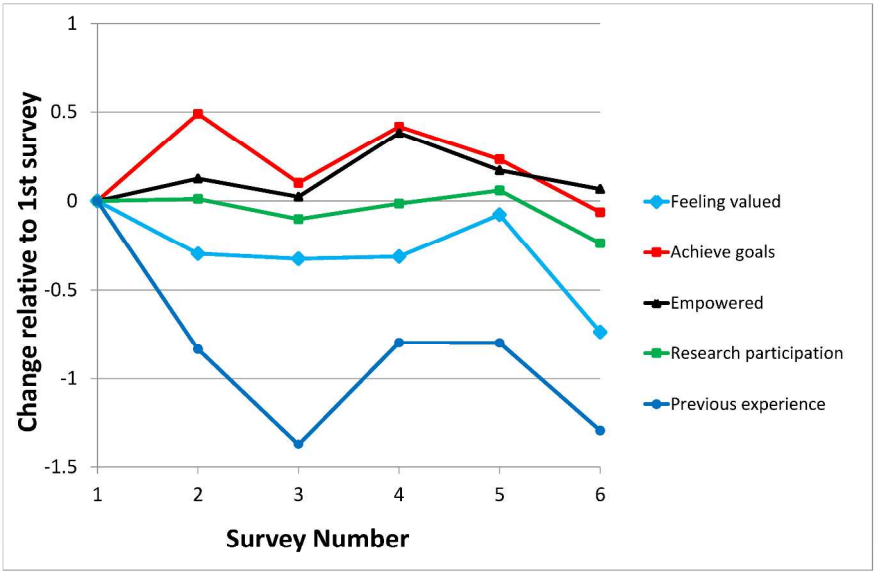

Fig 2. Changes in Likert score over time within factors and over all individuals.
296x209mm (300 x 300 DPI)

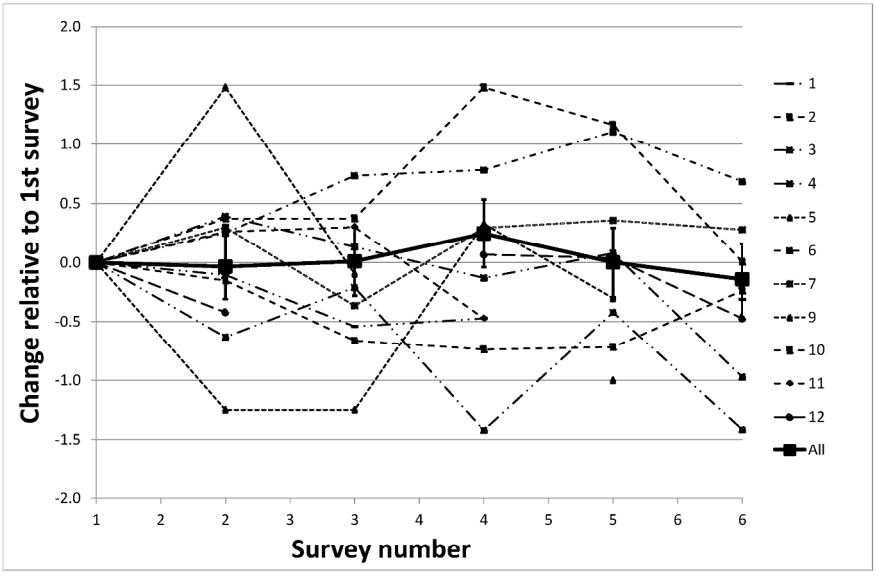

Fig 1. Changes in Likert score over time within individuals and over all individuals.
296x209mm (300 x 300 DPI)

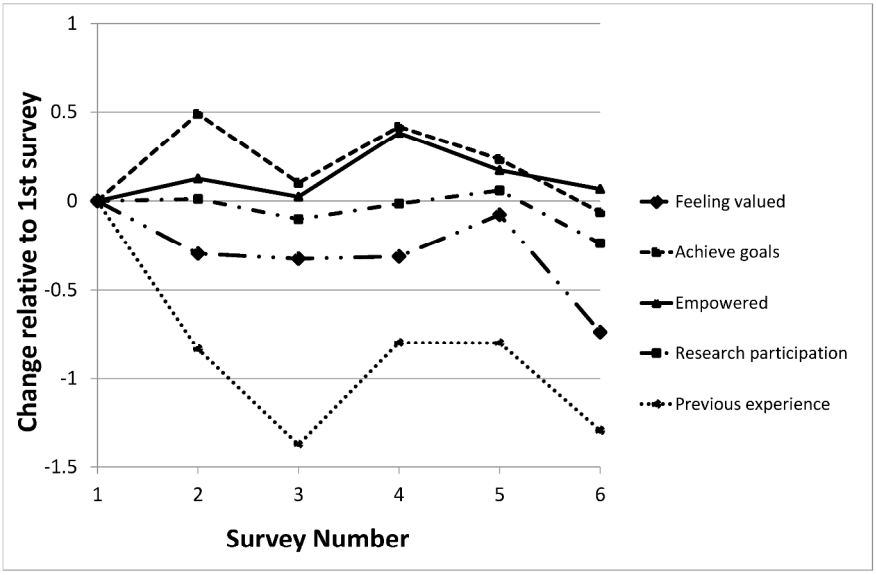

Fig 2. Changes in Likert score over time within factors and over all individuals.
296x209mm (300 x 300 DPI)

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Application of a tool for the evaluation of public & patient involvement in research

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1

Application of a tool for the evaluation of public & patient involvement in research

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Abstract

Objectives: Public and patient involvement (PPI) is required at all stages of research by many funding bodies such as the NIHR. Given the high priority of PPI within NIHR research programmes and the associated costs it is important that the process of involvement and impact of PPI on health services research is evaluated. We aimed to develop a tool to quantitatively evaluate the quality of PPI in research from a PPI participant's perspective in order to inform the researchers about absolute level of quality (cross-sectional aspect) and changes in quality over time (longitudinal aspect).

Setting: A primary care patient safety translational research centre.

Participants: The 12 members of the research user group (RUG) of Greater Manchester Primary Care Patient Safety Translational Research Centre.

Interventions: By their own choice each RUG member supported a specific research theme. The level of involvement varied from commenting on documents through to designing their own research projects.

Primary and secondary outcome measures planned:

- Measure absolute score and change in score over time in a 9 point Likert score within individuals.
- Compare Likert scores before undertaking PPI with scores after PPI activities.
- Evaluate the usefulness of a questionnaire based on a theoretical framework of personal and research factors.

Results The questionnaire had an acceptable to good level of internal consistency (Cronbach's alpha 0.74 – 0.81). The majority of the individuals met their initial expectations (11/12) and scored high across all factors. There was no significant change over time in the aggregate score over all factors and all individuals but there were differences within individuals and factors. A ceiling effect limited the questionnaire's usefulness to measure increasing scores.

Conclusions The questionnaire has been useful in evaluating the early stages of a PPI group and may be generalizable to another setting.

Article summary

Strengths of this study

- We have used questions based on a framework for quality in PPI to quantitatively evaluate PPI in research for the first time.
- The questionnaire showed good internal consistency between factors identified in a theoretical framework and was discriminatory in identifying individuals with decreasing scores for the quality of their experience of PPI.
- The questionnaire simultaneously addressed both absolute opinions and changes over time avoiding bias potentially arising when using relative measures.
- Using a within subject random effects regression analysis allows an estimate of overall change in score allowing monitoring of overall PPI quality even though individual PPI participants may enter or leave the PPI group.

Limitations of this study

- A ceiling effect made the questionnaire less useful for measuring increasing scores.
- Evaluating the Cronbach's alpha in another PPI group is needed to increase the confidence in the internal consistency of the questionnaire.

Background

The National Institute for Health Research (NIHR) research programmes require active involvement of patients and the public (PPI) at all stages of research, for example in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.[1] In the same way that the public have a right to have a say about services that are provided for them, they also have an ethical right to oversee and influence the direction taken by research into healthcare provision.[2,3] The Greater Manchester Primary Care Patient Safety Translational Research Centre (Greater Manchester PSTRC) is an NIHR funded Research Centre addressing patient safety in primary care settings.[4] Within the Greater Manchester PSTRC, after an open public call for recruitment, a Research User Group (RUG) was established in September 2013 to fulfil both a strategic governance role and contribute PPI to research activities. Given the high priority of PPI within Greater Manchester PSTRC and NIHR research programmes it is important that the process of engagement and impact of PPI on health services research is evaluated. Although researchers, members of the public and policy makers believe that it is possible to evaluate the impact of PPI on research it rarely happens.[5]

An individual has many personal reasons for being involved in PPI and these can be encouraged or discouraged by the structures or processes of research and/or the relationships with the researchers. A published theoretical framework aiming to assess the quality of PPI in a research context identified the underlying concepts or factors outlined in box 1.[6] We aim to use the questions provided with this framework to quantitatively evaluate the quality of the PPI within the RUG that may be generalised to other settings. This research aims to address the broader questions below.

1. Do the questions address the same underlying concept as defined by the theoretical framework?
2. Have the *a priori* expectations of the PPI participants been met?
3. How well is PPI functioning in terms of personal and research factors?
4. Is the quality of the PPI changing over time?
5. How strongly are the scores for personal factors associated with those for research factors?

Box 1. Quality involvement framework factors in evaluating the quality of PPI in research [6]
Personal factors
1. Being valued *e.g.* being paid and treated hospitably
2. Achieving one's own goals through involvement
3. Feeling able to make a contribution (empowered)

Research factors (relationships and ability to participate)
4a. A clear role for PPI in research and supportive structures e.g. motivated researchers, adequate funding and access to guidance on the processes of research
4b. Support at the organisational level and by existing ethical and governance systems
5. Application of previous experience as a service user or supporting research

Methods

The RUG consists of 12 members with an elected chair that met every 4-6 weeks between Sept13 and Apr14 (6 times in total). RUG members each support a specific research theme (by their own choice from medication safety , multimorbidity, general practice, interface and informatics) or the core theme which focuses on administration and PPI. Expenses are paid at the INVOLVE rate which

depends on the individual circumstances and the nature of the task (e.g. the daily committee fee is £150).[7] RUG members may be involved at all levels and stages of research from commenting on documents to designing their own projects.

The questionnaire [6] was adapted to the specific context of the Greater Manchester PSTRC and a further question assessed whether or not the PPI group (RUG) followed the ground rules that they developed among themselves (Appendix 1). Whether or not the RUG members met their own expectations was assessed by comparing an expectations questionnaire with the evaluation questionnaire. The expectations questionnaire consisted of twelve questions adapted from the evaluation questionnaire by replacing "Are you able to…" with "Do you expect to be able to…" etc (denoted E in Appendix 1). The expectations questionnaire was completed before the first RUG meeting and the evaluation questionnaire was completed on-line within 1 week of each RUG meeting. The question order was randomised for each individual and each administration.

Responses were measured on a 9 point Likert scale. In order to address research question 1 the internal consistency of the responses within each factor on the first administration was estimated by Cronbach's alpha. To address research question 2 a paired t test was used to compare the score in the expectations questionnaire with the mean score across all the surveys for each question within each individual. Research question 3 was addressed by reporting the mean response scores over all 6 surveys at the level of each factor (1-5, Box 1) and each participant, each factor across all participants and across all factors and all participants. Research question 4 was addressed by estimating the change in response score using multilevel mixed effects linear regression models with survey number as the predictor in Stata 13. For estimates of change within individuals and factors a 2 level model where the dependent variable was the response score nested within questions (the random effects or higher level in the model) was used. For estimates of change across all individuals a similar 3 level model included random effects on question numbers and individuals *i.e.* the response variable was nested within questions nested within the individuals. The results are presented as the change in response score relative to the first survey (assuming a linear trend) over the 6 surveys for each factor and across all factors. The question about adherence to the RUG ground rules (Q22, Appendix 1) was a single item Likert-type scale therefore a non-parametric approach was taken (Kendall tau rank correlation coefficient).[8] To address research question 5 the mean response scores for personal factors within surveys and individuals were compared with the scores for research factors using a 3 level mixed effects regression model. The dependant variable was the mean response score for personal factors nested within survey number and individuals (random effects) with mean response score for research factors as the predictor.

The use of regression models to analyse Likert scale data remains a long standing debate. [9] Arguably these data might be less likely to violate the assumptions of a linear regression in that it is truly Likert scale data as it uses several questions to address the same underlying concept and the wider 9 point scale was used. However the analysis was repeated using an ordered logistic regression model (ologit in Stata) to check that the assumptions made by the linear regression did not substantially alter the results. The advantage of the linear regression is the capacity to include random effects using Stata, *i.e.* to allow each individual to vary independently. An interim analysis was undertaken after 3 administrations of the questionnaire and feedback was provided to the researchers and the RUG.

All members of the RUG gave informed consent for the evaluation. This paper was circulated amongst the RUG and their comments are considered in the discussion.

Results

The questionnaire performed well across all factors with an acceptable to good level of internal consistency within each factor 1-5 (Cronbach's alpha 0.74 – 0.81) for survey 1. Out of 1159 potential responses to questions 1-19, 86 (7%) were answered "not applicable", these were distributed equally across the questions and omitted from the analysis. Just one RUG member expressed difficulty in understanding the meaning of questions 3, 7, 11, 12 and 20.

The expectations questionnaire was completed by 11/12 (92%) RUG members and the survey completed 61 times out of 65 potential completions (94%). RUG members had high *a priori* expectations (mean overall score 7.2, Table 1) and these expectations were largely met (mean score over all members and all surveys 7.3, table 1). However one individual's experience did not meet their initial expectations (8.2 cf. 7.1, P=0.02; individual 5, Table 1); this member subsequently resigned.

The whole group score over all factors was high (7.3 ±0.04, Table 2) and over all RUG members and factors there was no significant change in score (-0.02, -0.06, 0.02; Table 2). The estimated change in individual scores and across the whole group is shown in Fig 1. At the individual level there were 3 individuals showing an overall decreasing trend and one with an increasing trend (3,9,11,6, Table 2).

Scores were high for both personal and research factors over the whole group (7.0 – 7.8, Table 2) and factors 2-5 (achieving own goals, empowered, sufficient research support and relevance of previous experience) showed no significant change in score over time (Fig 2). However within factor 1 (being valued) the small decrease in score across the whole group approached significance and occurred mostly between surveys 5 and 6 (-0.07; -0.15, 0.01, Table 2 & Fig 2). This was driven by 3 individuals with a small but significant decline in their scores (1,3,9, Table 2). One individual reported a significant decrease in their ability to achieve their own goals (10, Table 2). Another individual reported a significant decrease in feeling empowered (4, Table 2) but two reported a significant increase in empowerment (6,7, Table 2). One individual reported a decline in score for research factors (3, Table 2). There was no change in opinion about the value of previous experience over all 6 surveys but there was a significant decline in the belief that previous experience was helpful between surveys 1 and 3 (-1.47; -2.58, -0.35). The RUG followed its own ground rules and this remained stable across all the surveys. Examples of the raw scores and the associated change estimated by the multilevel regression model are shown in Table 3 to assist with interpretation.

There was a significant association between responses for personal and research factors (0.41; 0.17, 0.65). The majority of the variance in the model was explained by the individual and survey number (intracluster correlation coefficient=0.93). Three members of the RUG resigned during the survey period. One individual only completed the questionnaire twice and gave low scores (8, Table 2). Another resigning member scored showed no change in score (+0.11, -0.06, 0.28; 5, Table 2) although their expectations score was higher than their mean survey score (5, Table 1). A third resigning member showed decreasing satisfaction over time (-0.14, -0.26, -0.03; 11, Table 2). The other two individuals showing a pattern of significantly decreasing scores resigned within 3 months of the survey period (3,9, Table 2). All cited practical reasons for their resignation such as re-location or other time-consuming commitments.

Repeating the analysis using an ordered logistic regression model did not alter the interpretation of the results.

Discussion

The two main aims of this survey were to apply the questions and theoretical framework recommended by Morrow et al [6] and to evaluate the PPI in Greater Manchester PSTRC from the participant's perspective. Cronbach's alpha showed acceptable to good internal consistency suggesting that the same underlying concept was addressed by all the questions within the factors (research question 1). With respect to the second research question the RUG had high expectations of the PPI which were largely met and overall scores representing levels of feeling valued, achieving one's own goals and feeling empowered were high, as were the overall scores representing the quality of the relationships with the researchers and opportunities to participate (third research question). The statistical method allowed viewing of the change in score over time adjusted for the differences in individual absolute scores (research question 4). The modest decline in feeling valued (factor 1) over time needs to be addressed. The high scores created a ceiling effect thereby reducing the potential to measure increasing scores. For example in Table 3 it is clear that one individual could not record increased empowerment as they were already giving the maximum score of 9,9,9. This is always a potential problem when using a finite scale aiming to simultaneously measure absolute and change in score. In future versions of the questionnaire alternative versions of the scale labels could be tried [9] or the Likert scale widened or replaced with a visual analogue scale. However maintaining high scores could be considered positive given that enthusiasm for most activities will naturally wane over time. It is arguable whether or not high expectations should have been encouraged at recruitment as this might lead to unrealistic expectations of the influence of the group.

The association between scores for personal and research factors (research question 5) is consistent with the hypothesis that higher levels of participation in research will lead to higher personal satisfaction but does not provide evidence for a causal relationship. It could equally be argued that individuals with higher levels of personal satisfaction are more likely to look for, or be open to, research opportunities.

The evaluation was intended to highlight any problems at an early stage so that appropriate action could be taken. A preliminary analysis after the 3rd survey suggested that some participants desired more research opportunities. As a consequence more involvement opportunities were offered at theme / project level. This coincided with a small overall increase in scores between survey 3 and 4. However it is possible that this led to members feeling overburdened leading to a small decrease in scores between survey 4 and 5.

An important question is whether or not a decrease in scores was observed leading up to the resignation of some RUG members. With hindsight there were some indicators of dissatisfaction leading up to resignations that occurred during the survey period; one individual failed to meet their expectations score, another had low scores right from the start and one showed an overall decrease in score. The other two individuals showing a pattern of decreasing scores resigned within 3 months of the survey period. RUG members showing similar patterns should receive extra support in future. However while the questionnaire may be able to retrospectively identify changes in scores it is less suited to an alert function; at least 3-6 months of data is required to identify a significant change in score. The wide variation of the perceived value of previous experience was surprising; this might be expected to be stable over time (Fig 2).

In the discussions with the RUG following distribution of this paper some valuable insights were gained. One point was that the high response rate might be explained by a sense of obligation due to payment of expenses and it should not be assumed to mean that the questionnaire was acceptable. Another point raised was that they were not involved in the study design so the questionnaire may

not reflect what they believe to be important. One aim of the questionnaire was to provide an objective evaluation based on generalisable concepts (the theoretical framework) rather than the opinions of this specific PPI group but also there was a practical reason in that the expectations questionnaire had to be designed before the 1st RUG meeting. Another constructive suggestion was that a question be added addressing whether the level of involvement is burdensome, too little or about right.

Although previous work has defined the norms and values underlying PPI in research [10-12] we are not aware of any other quantitative evaluations of the quality of PPI from the perspective of the participants over time. Our approach focuses on norms rather than values such as transparency or moral and ethical concerns. The CIROP tool measures the impact of research partnerships on the community [13] whereas we seek to evaluate the quality of involvement in the research process.

This analysis focuses on quality from the perspective of individuals participating in PPI but analysis is underway to set it within the context of quality in terms of impact and the researcher's perspective. Further work to explore whether the RUG had the factors identified in the theoretical framework in mind when completing the questionnaire is required to provide evidence of face validity for the questionnaire, as well as repeating the Cronbach's alpha measurements in another PPI group. Future work should address the ceiling effect [14] and other modifications that will make the questionnaire more responsive so that it can identify individuals who may benefit from extra support in a more timely fashion.

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Competing interests: None

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Ethical approval: University of Manchester Ethics Committee Approval 13172

Data sharing statement: Raw data (numerical only) is available from jill.stocks@manchester.ac.uk

Contributorship:
SJS designed, administered and analysed the questionnaire and wrote the manuscript
SG identified the theoretical framework, designed the questionnaire, wrote the ethics application and commented on the manuscript
SG, SCS assisted with study design and commented on the manuscript.

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Figure legends

Fig 1. Changes in Likert score over time within individuals and over all individuals.

Fig 2. Changes in Likert score over time within factors and over all individuals.

Table 1. Comparison of mean expectations and evaluation survey scores.

ID[+]	No of surveys	Mean score expectations ± SD	Mean score surveys 1-6 ± SD	P value Paired T test (by question)
1	5	7.6 ±0.33	8.0 ±0.13	0.28
2	6	6.4 ±0.47	6.1 ±0.20	0.67
3	6	6.9 ±0.38	7.4 ±0.11	0.24
4	6	8.3 ±0.47	7.7 ±0.15	0.32
5*	5	8.2 ±0.41	7.1 ±0.18	**0.02**
6	6	6.8 ±0.69	7.6 ±0.17	0.35
7	6	6.1 ±0.87	7.6 ±0.13	0.15
8*	2	6.2 ±0.55	5.1 ±0.37	0.15
10	6	7.2 ±0.37	7.0 ±0.16	0.63
11*	4	8.6 ±0.31	8.4 ±0.07	0.48
12	5	6.9 ±0.60	7.7 ±0.18	0.16
All	6	7.2 ±0.17	7.3 ±0.06	0.97

[*]Members who resigned from the RUG during the analysis period

[+]One individual did not complete the expectations questionnaire

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Table 2. Mean scores and change in score over all evaluation surveys (1-6) within individuals and across the group

ID	No of surveys	Being valued (Q1-6)		Achieving own goals (Q7-9)		Empowered (Q10-12)		Research relationships & level of participation (Q13-19)		Experience as a service user or supporting research (Q20-21)		All factors (Q1-19)		Follow ground rules (Q22)	
		Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Mean ±SD	Mean change 95% CI	Median range	Tau-b P value
1	5	8.2 ±0.16	**-0.21 -0.36, -0.06**	8.4 ±0.25	-0.03 -0.27, 0.22	8.1 ±0.25	+0.08 -0.20, 0.37	7.8 ±0.18	-0.03 -0.20, 0.13	9.0 ±0.00	-	8.1 ±0.10	-0.07 -0.17, 0.03	7 4-8	0.55 0.47
2	6	5.2 ±0.29	+0.01 -0.33, 0.36	6.2 ±0.36	+0.34 -0.02, 0.71	6.4 ±0.47	+0.29 -0.01, 0.56	6.3 ±0.25	-0.07 -0.27, 0.13	8.2 ±0.47	+0.00 -0.26, 0.27	6.0 ±0.16	+0.08 -0.07, 0.23	7 6-7	-
3	6	7.3 ±0.17	**-0.31 -0.48, -0.15**	7.1 ±0.22	-0.14 -0.37, 0.08	7.3 ±0.24	-0.13 -0.31, 0.05	7.5 ±0.14	**-0.22 -0.35, -0.10**	7.3 ±0.21	-0.04 -0.30, 0.21	7.3 ±0.09	**-0.22 -0.31, -0.14**	8.5 7-9	0.23 0.68
4	6	6.9 ±0.20	-0.08 -0.31, 0.16	7.9 ±0.30	-0.23 -0.45, 0.01	7.8 ±0.37	**-0.47 -0.76,-0.17**	7.7 ±0.23	-0.09 -0.25, 0.07	9.0 ±0.00	-	7.5 ±0.14	-0.17 -0.29, -0.06	7.5 7-8	0.77 0.08
5*	5	6.7 ±0.29	-0.04 -0.42, 0.34	7.2 ±0.31	+0.03 -0.29, 0.35	7.1 ±0.28	+0.17 -0.12, 0.46	7.1 ±0.24	+0.24 -0.03, 0.52	5.8 ±0.36	+0.01 -0.26, 0.28	7.0 ±0.14	+0.11 -0.06, 0.28	7 7-8	0.26 0.77
6	6	7.5 ±0.24	+0.18 -0.08, 0.43	7.4 ±0.33	+0.01 -0.30, 0.31	8.4 ±0.23	**+0.28 0.07, 0.48**	7.6 ±0.24	+0.19 -0.01, 0.39	7.2 ±0.77	-0.07 -0.32, 0.19	7.7 ±0.13	**+0.17 0.04, 0.30**	9 8-9	0.18 0.82
7	6	7.5 ±0.17	+0.07 -0.10, 0.24	7.2 ±0.32	-0.01 -0.21, 0.19	7.4 ±0.33	**+0.27 -0.06, 0.49**	7.7 ±0.17	+0.01 -0.13, 0.15	6.8 ±0.46	-0.04 -0.29, 0.21	7.5 ±0.11	+0.08 -0.02, 0.17	8 8-9	0.00 0.38
8*	2	4.2 ±0.47	-0.92 -2.59, 0.76	4.3 ±0.49	+1.33 0.80, 1.87	5.4 ±0.93	+0.46 -0.23, 1.16	5.4 ±0.49	0.00 -0.69, 0.69	8.5 ±0.29	-0.05 -0.31, 0.22	4.9 ±0.29	-0.03 -0.82, 0.76	5.5 5-6	-
9	4	5.8 ±0.51	**-0.61 -1.08, -0.13**	6.2 ±0.59	-0.48 -1.15, 0.19	6.5 ±0.56	-0.22 -0.69, 0.25	6.5 ±0.42	-0.16 -0.48, 0.16	8.9 ±0.14	-0.04 -0.31, 0.22	6.3 ±0.25	**-0.34 -0.58, -0.10**	8 6-9	0.55 0.47
10	6	6.8 ±0.26	-0.10 -0.39, 0.18	6.4 ±0.23	**-0.34 -0.54, -0.13**	7.0 ±0.38	-0.08 -0.35, 0.19	7.2 ±0.19	0.00 -0.15, 0.14	8.8 ±0.18	-0.05 -0.30, 0.21	7.0 ±0.13	-0.08 -0.19, 0.03	7 6-7	0.63 0.29
11*	4	8.4 ±0.11	-0.06 -0.24, 0.12	8.3 ±0.13	-0.03 -0.25, 0.18	8.5 ±0.16	-0.19 -0.41, 0.04	8.5 ±0.14	**-0.24 -0.46, -0.02**	8.7 ±0.18	-0.05 -0.32, 0.21	8.4 ±0.07	**-0.14 -0.26, -0.03**	9 9-9	-
12	5	7.5 ±0.16	-0.06 -0.21, 0.08	6.9 ±0.57	+0.10 -0.18, 0.38	7.8 ±0.30	+0.03 -0.16, 0.23	8.1 ±0.13	-0.07 -0.19, 0.04	6.50. ±0.27	+0.02 -0.28, 0.24	7.7 ±0.13	-0.02 -0.11, 0.06	9 9-9	-
All	61/65 (94%)	7.0 ±0.09	-0.07 -0.15, 0.01	7.1 ±0.12	-0.02 -0.12, 0.08	7.4 ±0.11	+0.03 -0.06, 0.12	7.4 ±0.07	-0.02 -0.07, 0.04	7.8 ±0.15	-0.03 -0.17, 0.10	7.3 ±0.04	-0.02 -0.06, 0.02	8 4-9	0.13 0.24

*Resigned

Table 3. Examples of raw scores and resulting change in score estimated by linear regression

Mean change 95% CI	Change in factor 3 (Empowered)	Survey number					
		1	2	3	4	5	6
-0.47 (-0.76, -0.17)	Sig ↓	8,9,9	8,9,9	6,8,9	7,9,9	7,8,9	3,6,8
+0.28 (0.07, 0.48)	Sig ↑	6,8,9	8,8,9	7,8,9	8,9,9	9,9,9	9,9,9
-0.08 (-0.35, 0.19)	No change	m,7,9	5,7,9	m,7,8	6,6,8	3,7,8	7,7,8

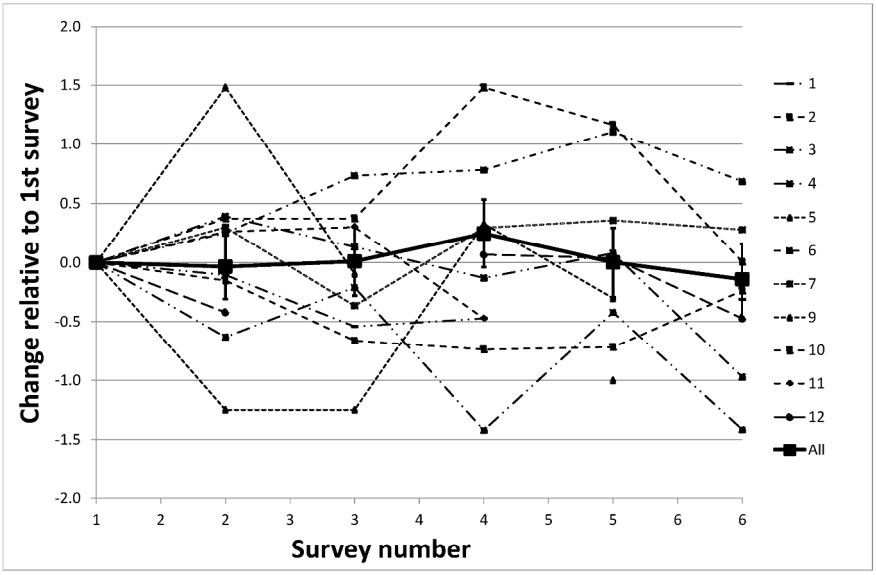

Fig 1. Changes in Likert score over time within individuals and over all individuals.
296x209mm (300 x 300 DPI)

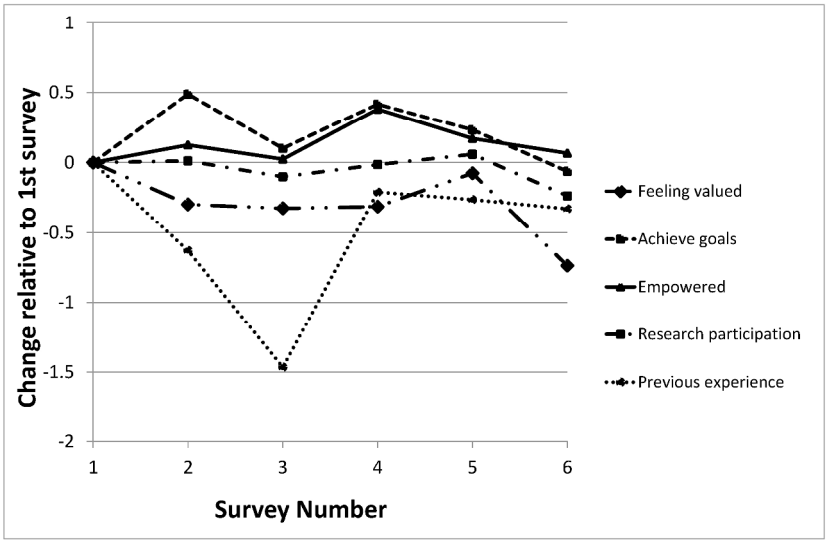

Fig 2. Changes in Likert score over time within factors and over all individuals.
297x210mm (300 x 300 DPI)

Appendix 1

List of questions – all responses were on a 9 point Likert scale with a free text option. E indicates used in the expectations questionnaire.

Factor 1 -

1E. Are you able to access GM PSTRC resources (e.g. expenses, facilities, information)?
2E. Are you able to make a contribution to the research within the GM PSTRC?
3E. Are you able to discuss research within the GM PSTRC?
4E. Are you able to influence decisions about how to do the research within the GM PSTRC?
(This is in a very general sense and might include methodology, timescales, research proposals, recruitment but other decisions should be considered too.)
5E. Are you able to express your views about research projects within the GM PSTRC?
6E. Are you able to take on new research challenges within the GM PSTRC?

Factor 2 -

7E. Is there potential for you to choose the type of role you play in the GM PSTRC RUG?
8E. Is there potential for you to bring your own ideas and values to the GM PSTRC?
9E. Is there potential for you to gain status, expertise or credibility because of your involvement in the GM PSTRC RUG?

Factor 3

10. To what extent do you feel valued as a partner within the GM PSTRC?
11. To what extent do you feel you are able to make an impact on the research undertaken by the GM PSTRC (i.e. how empowered or effective do you feel)?
12E. Is it acceptable that different people have different responsibilities and decisions to make about the research within the GM PSTRC?

Research context 4a

13. To what extent do you think the researchers in the GM PSTRC have the right reasons for wanting to work with you?
14E. Do you think the payment for your involvement in the GM PSTRC RUG is sufficient?
15. Do you have enough information about the research that is undertaken in the GM PSTRC?
16. Are the staff within the GM PSTRC supportive?

Research context 4b

17E. Are the skills/experience needed for the GM PSTRC RUG clear to you?
18E. Are you aware of the legal and ethical guidelines for research (e.g. confidentiality)?
19. Do you feel your involvement is valued by the GM PSTRC partners? e.g. Salford Royal NHS Foundation Trust/University of Manchester/Clinical Commissioning Groups (CCGs) as well as by the GM PSTRC?

Research context 5 – value of previous experience as healthcare user or supporting research

20. Is your involvement in the GM PSTRC RUG helped because of any previous experience you have had as a healthcare user either personally or through relatives/ friends/ colleagues etc
21. Is your involvement in the GM PSTRC RUG helped because of any previous experience you have of supporting research studies?
(This refers to any research experience e.g. as a participant in a trial or through patient public engagement activities)

Additional question

22. How well does the GM PSTRC RUG follow its ground rules?