



Research Design Service Involvement Forum review

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Summary

The Research Design Service (RDS) Involvement Forum is a shared learning group set up by INVOLVE in 2008 for staff with a public involvement role in the 10 Research Design Services. This review, using a questionnaire survey, was intended to assess whether the Forum was achieving its purpose and members were satisfied with the way the Forum was run.

Feedback from members suggested that the Forum serves useful functions for the members, the regional RDS and the RDS nationally. The most common benefits described by members were the opportunities for networking and sharing learning, good practice, challenges and difficult issues. Respondents to the survey indicated these helped them to improve the practice and delivery of public involvement for the RDS. Almost all respondents were satisfied with the format of the Forum.

Some members expressed interest in developing the Forum to have a more strategic view and working collaboratively with a focus on shared public involvement objectives for the RDS. This coincided with the RDS developing a more formal structure for national collaboration on strategy and shared aims across a number of work areas as they move into the next contracting period (2013-18). Following discussion of the review findings, Forum members and INVOLVE are developing options for the group to be re-organised in order to effectively meet the dual aims of shared learning and collaboration on specific objectives for the RDS.

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1. Introduction

The Research Design Services (RDS) are a network of 10 regional services which support researchers to develop and design high quality research proposals for submission to the National Institute for Health Research (NIHR) and other national, peer-reviewed funding competitions for applied health or social care research. Each RDS has a responsibility to provide advice and support for public involvement in research design.

The RDS Involvement Forum was set up by INVOLVE in 2008 when the RDS were first commissioned. The Forum currently meets three times a year. The overall aims are to:

- facilitate a shared understanding about public involvement across the RDS
- discuss and address issues of common concern in relation to public involvement in the RDS
- facilitate access to support and resources that are available from INVOLVE and other organisations
- exchange ideas, strengthen skills and share examples of good practice to develop public involvement in research.

Membership of the Forum is open to all those who have a lead role in promoting and supporting public involvement in the RDS. The description for membership was purposefully broad in the Terms of Reference so that it would encompass the different posts which contribute to public involvement across the RDS. These include a range of public involvement advisor posts (whether dedicated to public involvement or involvement being one part of their role), RDS Directors and other senior staff with the strategic lead for public involvement and other staff in various support roles.

Becoming a member of the Forum is managed informally. People send a membership request to INVOLVE in agreement with their RDS. They are then placed on one of two email distribution lists as appropriate. The primary list is for those with

the main role for public involvement in their RDS and they will usually attend (or send apologies for) the Forum meetings. The secondary list is for others who support public involvement in the RDS and is used to copy them into communications about meeting papers and other updates. All members have access to a password protected online repository of meeting and other relevant papers.

The current Terms of Reference for the Forum, agreed with Forum members in 2009, are available in Appendix A.

In 2012, it is timely to undertake a review of the RDS Involvement Forum. After four years, it is important to check whether the function (what it is for) and format (how it is run) of the Forum is fit for purpose and relevant to the Forum members, the RDS and INVOLVE. The findings of the review will support ongoing discussions about creating useful links between the Forum and the RDS Directors.

2. What we did

The idea for the review was suggested by INVOLVE and discussed with Forum members at a meeting in May 2012. Forum members agreed it would be useful to carry out a review, led by INVOLVE with the active involvement of Forum members. While it was most practical to carry out an internal review it was recognised that this may affect the responses received. Respondents may have felt that, as INVOLVE facilitates the Forum, they could not be as honest about it as they would have been had an external review been carried out. Forum members discussed the need for critically constructive reflection to support the future development of the Forum and the option of responding anonymously was agreed.

In discussion, it was agreed to use a questionnaire to collect Forum members' feedback, which would be compiled into a draft report by INVOLVE. Forum members would review and comment on the draft report before further discussions at the October 2012 meeting of the RDS Involvement Forum.

At the May meeting, Forum members began to formulate a list of relevant questions. INVOLVE then reviewed these suggestions and devised a short questionnaire. Three members of the Forum further reviewed the questionnaire and suggested amendments. The final version of the questions was entered into Survey Monkey for completing online (the survey questions are in Appendix B). Respondents were given the option of entering the RDS in which they are based and also their name. The results from the review are not reported by RDS or with any identifying characteristics.

Invitations to complete the questionnaire were sent to all RDS staff on the two email distributions lists. This was 29 people in total – 16 on the primary list and 13 on the secondary list.

The review included closed and open ended questions. In this report, we give the number of responses to the closed questions. For the open ended questions, we have collated the responses and provide a thematic summary giving an indication where there was agreement or divergence in views among the respondents. We have also selected some direct quotes to illustrate some of the themes.

Responses to the survey

Eighteen survey responses were received. At least one person responded from each of the 10 RDS. Some respondents chose to leave some questions blank, therefore not all the total responses reported add up to 18.

Thirteen respondents regularly attended the meetings, four attended occasionally, while one never attended the meetings. This suggests that most responses were from the people on the primary email distribution list (not everyone gave their name, so it's not possible to know exactly how many responded from each list).

Of the survey respondents, four worked full-time for the RDS, while 14 worked part-time. Of those who worked part-time for the RDS, the whole time equivalent (wte) was provided, which ranged from 0.1 to 0.8 wte.

Ten respondents indicated that their role is dedicated to public involvement, whilst eight have other main responsibilities so public involvement is only one part of their role.

Most respondents (12) used the online space for accessing meeting related papers, whilst only two indicated that they used the online space for sharing documents and other information. Six respondents sent the Forum papers to others in their RDS and seven were sent the Forum papers by other members.

3. Findings

3.1 Membership of the RDS Involvement Forum

Respondents mainly agreed (16) that membership of the Forum being open to those with a lead role for public involvement in the RDS was appropriate, with one respondent expressing disagreement. Later in the survey, one respondent suggested that membership could be better defined to ensure all those best able to participate in Forum meetings could do so:

"Lead people are often too busy to attend..., I think 'lead' should be removed so it is clear that any patient and public involvement (PPI) specialist in the RDS can attend."

Overall 12 respondents were supportive of other people participating in the Forum, with five respondents preferring no other involvement. Of those who supported other involvement:

- six respondents indicated the RDS Directors
- six respondents indicated other PPI leads from across the NIHR
- six respondents indicated PPI leads from outside the NIHR.

However, the open ended responses to this question indicated a preference for restricting core membership of the Forum to RDS personnel, with other groups from outside the RDS attending occasionally when relevant issues were being discussed and to support networking and joint working.

3.2 Usefulness and benefits of the Forum

As shown in Table 1, almost all the respondents thought that the RDS Involvement Forum was useful, with most rating it as very useful.

Table 1: How useful do you think the RDS Involvement Forum is to:						
	Very useful	Quite useful	Not very useful	Not at all useful	Total	
You personally in your role in the RDS?	11	6	0	0	17	
Your regional RDS?	9	7	1	0	17	
The RDS nationally?	11	5	0	1	17	

Usefulness to the respondents in their role in the RDS

The main way in which the Forum was useful to the respondents was through sharing ideas, keeping up-to-date and learning from each other (n = 14):

"The Forum provides a really useful opportunity to share ideas and experience that I can then develop and apply to my own work where appropriate."

"It gives me ideas and information from the perspectives of others in a similar position which would be very difficult to garner in any other way or as efficiently."

Six respondents valued the Forum for networking and the opportunity to meet with colleagues, for example:

"PPI colleagues are a resource and we need to feel we are a group, not isolated."

Four respondents mentioned the mutual support and confidence gained from working as a group.

These themes were reiterated when respondents were asked about the main benefits of the RDS Involvement Forum. Respondents gained benefit from the opportunities for sharing learning, good practice, challenges and difficult issues. They valued the mutual support from colleagues in similar roles. One respondent likened the Forum to a community of practice, others drew on concepts such as collective action and collaboration and one signalled the benefit of building up trust within the Forum so members could be honest about mistakes and challenges to help all learn and develop.

Usefulness to the regional RDS

While respondents indicated that the Forum was useful to their regional RDS, the strength of this view was slightly weaker than the usefulness to them personally and to the RDS nationally. Two respondents (including the one who indicated the Forum was not very useful to the regional RDS) suggested this was because their RDS did not currently take advantage of the benefits of the Forum. The main way in which the Forum was useful to the regional RDS was through sharing practice and ideas to improve public involvement in each RDS, including passing on information to other RDS advisors:

"The Forum enables the regional RDSs to remain outward focused. We share challenges and opportunities so that our own RDS benefits."

Usefulness to the RDS nationally

Almost all respondents thought the Forum was useful to the RDS nationally. This was mainly in relation to developing a national presence for public involvement and providing scope for collective influence and collaboration. One respondent thought

that there was scope for better recognition of the value of this national role for the Forum by the RDS.

The feedback on usefulness and benefits of the Forum indicated a slight divergence in views around the consistency of practice/activity for public involvement across the RDS. While a few thought that the Forum helped to achieve this, one thought there was scope for the forum to achieve greater consistency and one respondent thought that variation would always be a feature of the 10 different RDS.

Impact beyond the RDS

Members were asked if they thought the RDS Involvement Forum had an impact beyond the 10 RDS. Most respondents (12) thought that it did, while the remainder (6) were not sure or thought there was no impact.

When describing the impact beyond the RDS some respondents thought this was on other local and regional organisations, spreading good practice and know how. A few thought that, through INVOLVE, issues were fed into other parts of the NIHR and to the Department of Health.

Similarly, a small number of respondents identified the input from INVOLVE as a key benefit of the Forum, although one respondent was not sure why INVOLVE ran the Forum as they felt it could be run as effectively by its members.

One respondent thought that the RDS Forum should focus on the RDS and not have wider impacts, while another thought that the opportunity for the Forum to have wider impacts could be better developed in future.

3.3 Improving the usefulness of the Forum

Eleven respondents made suggestions on how they thought the forum could be more useful.

Five respondents thought the Forum could take a more strategic view, for example influencing the strategic direction of public involvement across the RDS nationally and contributing to the development of public involvement across the wider NIHR:

"The Forum could have a bigger role in influencing and developing PPI strategy across RDS nationally and respond to/feed into wider NIHR PPI issues and strategy."

Four respondents supported the idea of a Forum action plan, relating to core public involvement objectives for the RDS and working collaboratively towards achieving

this. One respondent thought this should concentrate on operational matters, for example, giving advice on PPI, improving quality and developing solutions to PPI challenges.

Two respondents thought there should be greater involvement in the Forum by members of the public who were involved with the RDS.

Effective links with the other RDS national groups

Fifteen respondents suggested ways in which effective links with the other RDS national groups (RDS Directors' Exchanging Ideas meetings and the communications group) could be developed.

Ten supported an overlap in membership between the groups. These Forum members were generally happy for a nominated person from the other groups to join the RDS Involvement Forum, with some stressing that this should be reciprocal, with Forum members also attending the other groups.

Three respondents suggested standing agenda items for each group to ensure that crossover of ideas and feedback was achieved. One person noted that this would require active management to be effective.

Two respondents thought that better communication within the regional RDS between staff members had scope to aid effective cross working – they felt this worked well in their area and could be better encouraged in other regions.

Two respondents suggested further discussion amongst the groups was required. One proposed developing effective links and another suggested all groups could contribute to a shared PPI strategy.

3.4 Satisfaction with the format of the Forum

Figure 1 (on the following page) shows the respondents satisfaction with the format of the Forum. Overall respondents were generally satisfied with the format. Fourteen respondents provided further explanations of their answers.

Most respondents reiterated that they were happy with three meetings a year although one person suggested having four meetings, while another suggested having only two. This respondent also commented that the group should limit the number of meetings it had each year and only meet when there is an agenda warranting it, rather than making an agenda to fit the schedule of meeting dates.

There were mixed views on the meeting locations. Four people felt that holding all meetings in London would be most convenient whilst one felt that it was difficult to get to London.

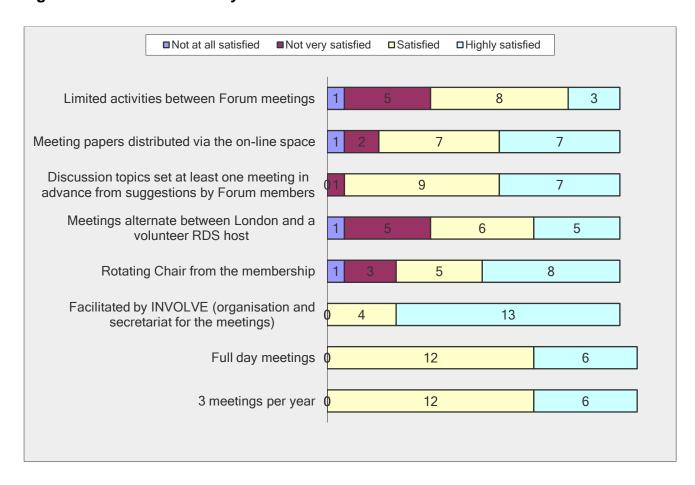


Figure 1: How satisfied are you with the current format?

A small number of respondents (3) explained that they do not like having a rotating chair format:

"The rotating chair feels a bit disjointed and no-one ever really wants to do it - would be better to have some continuity."

One suggestion was to have one chair to cover three meetings, possibly through a nomination and voting process. One person noted that they appreciated the current chair format.

A small number of respondents (2) noted that the online space was 'tricky' to use.

3.5 Improving the format of the Forum

Suggestions for improving the format of the Forum mainly related to the areas where there was some dissatisfaction expressed by respondents, that is location, rotating chair and activities between meetings.

One respondent suggested that it would be good to have the meetings in London, while another felt that only places involving relatively equal travel costs and time for the majority should be used.

Two respondents suggested that there should be only one chair of the group and that a rotating chair format should not be used.

A number of the respondents (7) said that that they would like the group to have more work, exchanges or activities between the meetings:

"Perhaps there could be more activity between meetings to keep up momentum and develop/take issues forward more."

However one respondent recognised that everyone is busy and may have limited capacity to do extra work. One person suggested that as there are limited activities in the Forum, it could signify that there is a low need for the group now that the RDS have become established.

3.6 Future activities for the RDS Involvement Forum meetings

Fifteen respondents provided a wide variety of suggestions of future activities for the RDS Involvement Forum meetings.

Many respondents suggested speakers or presenters for future meetings, with one suggestion to invite a guest speaker to each meeting. Common suggestions were to link with the NIHR programmes which fund research and invite lay reviewers and panel members to speak to the Forum or have talks from successful applicants of NIHR funding. Other suggestions were to invite speakers from the research networks and authors of papers on public involvement in research, or ask members of the Forum to present their public involvement in research work.

A wide variety of suggestions were made on work which the Forum could take forward:

- develop a forum strategy/action plan and be able to take decisions about what to implement
- consider some co-writing opportunities
- find out the Directors' perspective on the role of the Forum

- have a focused session about evidence and research into public involvement, which would include updates on research that Forum members are undertaking
- feedback on public involvement courses
- funding of PPI by different RDS
- how to work as a national RDS in the next tender
- discussions on how clinical trials units are implementing public involvement
- link with the Exchanging Ideas Meeting and the meeting for the communications leads.

3.7 Aspirations for the Forum

Fifteen respondents had suggestions for what they would like the Forum to achieve over the next three to five years. These suggestions covered a wide range of different areas which have been summarised under the following headings. The numbers in brackets indicate where more than one person made a similar suggestion.

Strategy, influence and action planning

- a group developed strategy and action plan (2)
- input into the broader RDS strategy/influence the RDS Directors (3)
- promotion of the RDS as leaders in PPI.

Sharing and mutual support

- cross regional advice and review of complex cases
- continuation of support for public involvement advisors (3)
- effective communication across the Forum members (2).

Joint working

- joint working across the NIHR (4)
- developing consistency and coordination for PPI across the RDS (2).

Quality improvement

- setting quality markers for PPI/systems for measuring quality and impact (4)
- securing more funding for PPI
- developing consistency in the PPI review process across the NIHR research programme
- training and development for PPI across RDS staff teams.

Focus on research design

- research on the impact of PPI in research design (3)
- developing resources for supporting PPI in research design
- holding a national PPI in research design conference.

Issues for service users/members of the public

- becoming a leading voice on user-led research
- exploring issues for involved members of the public.

4. Conclusion

Overall, the responses to the survey indicated that the RDS Involvement Forum serves a useful function for the public involvement leads in the RDS – this function has a positive impact for Forum members, the individual RDS, the network of 10 RDS and beyond. The benefits respondents described relate closely to the overall aims of the Forum set out in the Terms of Reference, with the most common benefits being opportunities for networking and sharing learning, good practice, challenges and difficult issues. Respondents indicated these help them improve the practice and delivery of public involvement in their respective RDS.

Respondents were generally satisfied with a number of aspects of the Forum format, including:

- frequency and length of meetings
- advance planning with members for discussions topics
- facilitation by INVOLVE
- using the online repository.

Respondents had varying views on other aspects of the Forum, including:

- developing a strategic view and/or action planning element
- activities between meetings
- locations for the meetings
- rotating chair arrangement.

The findings of this review suggest that the function and format of the RDS Involvement Forum is fit for the purpose intended and remains relevant to Forum members.

It was recognised at the start of the review that as INVOLVE facilitates the forum and was also leading on the review, this may impact on the responses received. It is difficult to know whether this did occur in practice. Given that the findings matched the informal feedback we receive about the Forum, we are reassured that the responses are an accurate reflection of the respondents' views.

5. Next steps

Following the review, all Forum members had the opportunity to feedback on a draft version of the report. The report was then discussed at the RDS Involvement Forum meeting on 16 October 2012, attended by two RDS Directors.

For the RDS Involvement Forum

The findings of the review and the discussion at the meeting confirmed the Forum is valued by its members and largely achieves its current aims. Members signalled strong support for continuing with the Forum.

There was also discussion, strongly supported by the Directors present at the meeting, to develop the strategic focus of the Forum, with members working collectively on national RDS PPI aims. It was proposed that this part of the Forum would report to the RDS Directors' Group.

Forum members plan to explore options for developing the Forum to retain the shared learning, peer support element, plus working collectively to achieve national RDS PPI aims. These options will consider effective models of chairing and continuity for the Forum as well as practical aspects such as regularity and length of meetings. It is envisaged this new model will be put in place early in 2013.

For the RDS

At the time of carrying out this review, discussions were underway to develop closer links between the Forum and the Directors' Exchanging Ideas Group. INVOLVE, the RDS Involvement Forum and the RDS Directors had all identified this was necessary. It has potential to promote ways for issues relating to public involvement in the RDS and more widely to be effectively communicated to RDS Directors. It will also enable the expertise of the public involvement advisors to be recognised as a valuable resource for the RDS nationally, supporting the strategic direction of public involvement in the RDS.

At the meeting on 16 October 2012, the ideas for promoting greater communication between the RDS Directors' Group and the PPI leads were supported by the RDS Involvement Forum. Members would like to see reciprocal, overlapping membership of both groups and standing agenda items at each meeting. These proposals will be discussed with RDS Directors, along with ideas for the revised format of the Forum.

For INVOLVE

It is of great benefit to INVOLVE to receive this detailed feedback about one of the three shared learning groups we facilitate. We are encouraged by the value

respondents placed on the Forum and its working methods. It forms a core part of INVOLVE's role to support the shared learning in the public involvement community that respondents have reported is achieved by the Forum.

INVOLVE remains committed to facilitating the shared learning, peer support function of the RDS Involvement Forum for as long as this is supported by the RDS. It would not be appropriate for INVOLVE to facilitate a group to work on delivering national RDS aims and strategic objectives, and which reports to the RDS Directors. However, INVOLVE would be keen to participate in these strategically-focused PPI meetings as appropriate.

INVOLVE

Research Design Service Involvement Forum

Terms of Reference and working methods

Purpose

The Research Design Service Involvement Forum was established by INVOLVE in 2008. It has been set up to provide a forum for those involved in promoting and supporting public involvement in research (see below for a definition of these terms) in the National Institute for Health Research (NIHR) Research Design Services (RDS).

The Forum aims to:

- facilitate a shared understanding about public involvement across the RDS
- discuss and address issues of common concern in relation to public involvement in RDS
- facilitate access to support and resources that are available from INVOLVE and other organisations
- exchange ideas, strengthen skills and share examples of good practice to develop public involvement in research.

Membership

Membership of the group is open to those who have a lead role in promoting and supporting public involvement in research in the RDS established in each Strategic Health Authority in 2008 and 2009.

Working methods of the Forum

The Forum has agreed to adopt a shared learning approach. This involves:

Forum meetings

- At least three meetings will be held each year organised by INVOLVE
- The chair for each meeting will rotate between members of the forum, this will entail:
 - devising the agenda in collaboration with INVOLVE prior to the meeting
 - chairing the forum meeting
 - receiving any feedback from Forum members after each meeting and communicating this to INVOLVE (anonymised where requested)
- Meeting topics will be generated by members of the forum
- Meetings will include small group discussions to share experiences and learning
- Other people may be invited to join forum meetings on a one-off basis to aid discussion of particular topic, for example as speakers, observers or invited guests
- Secretariat for the Forum will be provided by INVOLVE.

Sharing of information and resources

- Through the Forum meetings and electronic communications members will be able to share information and resources
- Members should be able to choose what they share and when they share it
- It is each member's responsibility to make it clear where a matter shall remain entirely confidential and not for discussion outside of the Forum
- When sharing documents, members should make it clear if there is a restriction as to:
 - o circulation of the documents beyond the Forum
 - copyright/use of the contents
- INVOLVE will facilitate the development of a web space for members of the Forum which will include a secure password-protected area to share resources.

Definition of terms

By 'involvement' in research, we mean an active partnership between the public and researchers in the research process, rather than the use of people as 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Public involvement in research is often defined as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

By 'public' we mean:

- patients and potential patients
- people who provide care or support on an informal (that is unpaid) basis
- parents/guardians
- people who use health and social care services
- disabled people
- members of the public and communities who might be targeted by health promotion, public health and social care
- groups asking for research because they believe they have been exposed to potentially harmful substances or products
- organisations that represent people who use health and social care services.

The term 'the public' is understood to include a rich diversity of people, whether defined by age, colour, race, ethnicity or nationality, disability, gender or sexuality, who may have different needs and concerns.

INVOLVE uses the term 'public involvement' to describe our area of work. We recognise that others, including the RDS will use alternative terms, such as public and patient involvement or consumer involvement.

INVOLVE Coordinating Centre/RDS Involvement Forum

October 2009

Appendix 2: Review questionnaire

Research Design Services Involvement Forum survey

A. Membership of the RDS Involvement Forum

*1. Do you work in the RDS:
C Full time
C Part time
If part time, please specify whole time equivalent e.g. 0.5
*2. Is your RDS role:
O Dedicated to public involvement (you do not have other main responsibilities)
O Public involvement is one part of your role (you do have other main responsibilities)
*3. Do you: (please tick one only)
C Regularly attend Forum meetings
Occasionally attend Forum meetings
Never attend Forum meetings
*4. Do you: (please tick all that apply)
Use the on-line space for accessing meeting related papers
Use the on-line space for sharing documents and other information
Send Forum papers to others in your RDS
Get sent Forum papers from other members
*5. Membership of the Forum is currently open to people working in the RDS with a lead role for promoting and supporting public involvement in research in the RDS. Do you agree with this?
O Yes
○ No
Any comments?

Research Design Services Involvement Forum survey *6. Do you think membership of the Forum should be open to any other people? (tick all that apply and please explain your answer) RDS Directors PPI leads from other parts of the NIHR PPI leads from outside the NIHR e.g. Universities, NHS Trusts, Charities ■ No other people Other (Please specify) We are asking for your name and RDS so that we know how much coverage this survey achieves. It will also allow us to follow up any queries about your responses if we need to. Your responses to the following questions will only be seen by INVOLVE Coordinating Centre staff. When we report on the review, we will not identify any individuals or their RDS. 7. Your name (optional) 8. Which RDS are you based at? (optional) C East of England East Midlands London North East North West South Central South East Coast South West West Midlands Yorkshire and the Humber

Function of the	Forum			
^k 9. How useful do	vou think the R	RDS Involvement F	orum is to:	
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^k 10. How useful d				
V	Very useful	Quite useful	Not very useful	Not at all useful
Your regional RDS				O
Please explain your answer				<u> </u>
*11. How useful d				
The DDS nationally	Very useful	Quite useful	Not very useful	Not at all useful
The RDS nationally	O	C	U	· ·
Please explain your answer				<u> </u>
Please explain your answer 2. What do you thin	nk are the main	benefits of the R	DS Involvement Fo	orum?

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5. What suggestink with other na	tional RDS grou				_
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6. What would yo ears? ease provide up			t Forum to ach	lieve over the	next 3-5
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Research Design Services Involvement Forur	n survey
20. Finally, do you have any suggestions of future active meetings? For example, meeting topics, speakers, issuguests/contributors.	
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	▼
Thank for your completing this survey.	