Appendix 1: Questionnaire

Welcome

Welcome to this collaborative survey about the dissemination of research results to study participants and patient groups.

The following questions are specific to your recent study published in 2014 or 2015 that we mentioned in our accompanying email.

[Screening question to identify trials with humans]

1) Did this clinical trial study include humans as participants?
   i) Yes
   ii) No, it was a laboratory experiment using animals
   iii) No, it was a preclinical trial without patients
   iv) No, there were no study participants
   v) This study was not a clinical trial

If they indicate ii), iii), iv) or v) on Q1 they should be thanked and routed out of the survey to the disqualification page

2) Please indicate which type of study this was:
   i) A trial with healthy volunteers
   ii) A trial where participants were enrolled into the study and these participants WERE patients
   iii) A trial where participants were enrolled into the study but these participants WERE NOT patients (e.g. they may have been carers, pregnant women, smokers, etc)
   iv) A trial (e.g. a cluster trial) where participants were not individually enrolled into the trial
   v) Other (please specify): _________________________________

If they indicate i) or ii) or iii) or v) on Q2 they should go to next question (Q4)
If they indicate iv) on Q2 ie patients were not enrolled they should go to Q10 (dissemination to patients outside of the trial)

3) What type of funding did the research team receive for this study? (Tick all that apply).
   □ Industry
   □ Non-industry (for example, public granting agency, private not for profit granting agency)
   □ No external funding
   □ Other (please specify): _________________________________

If they indicate i) or ii) or iii) or v) on Q3 they should go to next question (Q4)
If they indicate iv) on Q3 ie patients were not enrolled they should go to Q10 (dissemination to patients outside of the trial)

4) Did you or any of your coauthors have access to the participant identifiable data for this study?
   □ Yes, we had access to the participant identifiable data
   □ No, we worked on anonymised data and did not have the ability to link this to data that would identify the participants
   □ Other (please specify): _________________________________

5) Were trial participants asked if they wanted to be informed of the study results?
   □ Yes
   □ No
   □ Don’t know

6) Have the results of your study been disseminated to trial participants?
   i) Yes, the results have been disseminated to trial participants
   ii) No, but we plan to disseminate the results to trial participants
   iii) No, and we do not plan to disseminate the results to trial participants
   iv) Don’t know
   v) Other ______________________

If they respond (i) or (v ie Other) to Q6:

7a) Were trial participants offered documents or presentations written for an academic/clinical audience, such as the full study report, journal publications, an academic summary, etc?
   □ Yes
   □ No
   □ Don’t know
7a) If Yes, please describe what they were offered (you may tick multiple responses):
- Full study report
- Journal publication(s)
- Academic summary
- Other (Please specify): _____________________

7b) Were trial participants offered documents or presentations prepared specifically for lay readers, such as a lay summary or invitation to attend a workshop or meeting?
- Yes
- No
- Don’t know

7b_i) If Yes, please describe what they were offered (you may tick multiple responses):
- We sent trial participants a lay summary
- We published a lay summary on a website for trial participants to access
- We invited trial participants to attend a workshop or meeting
- Other (Please specify): _____________________

7c) Have trial participants been given their own individualised study results, such as outcomes, scores, or analysed data?
- Yes, these have been given to individual trial participants
- No, but we plan to give these to individual trial participants
- No, and we do not plan to give these to individual trial participants
- Don’t know
- Other _____________________

If they respond (ii) to Q6 ie they plan to disseminate:

8g) Will trial participants be offered documents or presentations written for an academic/clinical audience, such as the full study report, journal publications, an academic summary, etc?
- Yes
- No
- Don’t know

8g_i) If Yes, please describe what they will be offered (you may tick multiple responses):
- Full study report
- Journal publication(s)
- Academic summary
- Other (Please specify): _____________________

8f) Will trial participants be offered documents or presentations prepared specifically for lay readers, such as a lay summary or invitation to attend a workshop or meeting?
- Yes
- No
- Don’t know

8f_i) If Yes, please describe what they will be offered (you may tick multiple responses):
- We will send trial participants a lay summary
- We will publish a lay summary on a website for trial participants to access
- We will invite trial participants to attend a workshop or meeting
- Other (Please specify): _____________________

8g) Will trial participants be given their own individualised study results, such as outcomes, scores, or analysed data?
- Yes, these will be given to individual trial participants
- No, we do not plan to give these to individual trial participants
- Don’t know
- Other _____________________
If they respond (iii) to Q6 ie they do not intend to disseminate results:

9) Please explain why the research team does not plan to disseminate the results to trial participants?

If they respond (iv) to Q6 ie “don’t know if they disseminated to participants” they should be routed to Q10 on wider dissemination.

**Wider dissemination**

10) How did (or will) the research team share the results of this study with patients outside of those who took part in the trial?

<table>
<thead>
<tr>
<th></th>
<th>Already shared</th>
<th>Plan to share</th>
<th>Neither shared nor plan to share</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>By direct contact with relevant patient charities or patient groups</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Via informal patient communities (e.g. shared on social media)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Via presentations at conferences where patients are represented</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Via the mainstream media</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>By publishing lay summaries on the trial website or somewhere publicly accessible</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify): ________________________________</td>
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</tbody>
</table>

**External requests to disseminate**

11a) Which of the following parties suggested that the research team should disseminate results to trial participants?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal investigator for the study</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other members of the research team</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patient and public involvement (PPI) representative involved with the trial</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Research funder(s)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Ethical or institutional review board</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Academic institution</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Regulatory bodies</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify): ________________________________</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
11b) Which of the following parties suggested that the research team should disseminate results to other patient groups?

<table>
<thead>
<tr>
<th>Party</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal investigator for the study</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other members of the research team</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patient and public involvement (PPI) representative involved with the trial</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
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<td>Research funder(s)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Ethical or institutional review board(s) / IRB</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
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<td>Academic institution(s)</td>
<td>☐</td>
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<tr>
<td>Regulatory bodies</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Other (please specify):</td>
<td>☐</td>
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</table>

Other (please specify): ________________________________________________

Patient involvement

12) Please indicate if the research team asked (or plans to ask) trial participants, other patients, or lay groups to be involved with any of the following:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Already asked for this involvement</th>
<th>Plan to ask for this involvement</th>
<th>No plan to ask for this involvement</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpreting the study findings and potential impact of the study</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Contributing to the writing or commenting on drafts of the manuscript for publication</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Developing the content of the materials for dissemination to trial participants and other patients</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Selecting the most appropriate dissemination method or format to reach participants and other patients</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Presenting or sharing the results from the study with other patients or the public</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please specify): ___________________</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Confidence

13) In general, how confident do you feel about how to best disseminate results to study participants?
   - Not at all
   - Slightly
   - Moderately
   - Very
   - Extremely
   - Other: ______________________________

14) In general, how confident do you feel about how to best disseminate results to patients outside of those who took part in a study?
   - Not at all
   - Slightly
   - Moderately
   - Very
   - Extremely
   - Other: ______________________________

Barriers and challenges

15) Please describe the main barriers or challenges to disseminating results of your research to study participants?
   ______________________________________

16) Please describe the main barriers or challenges to disseminating results of your research to patients outside of those who took part in the study?
   ______________________________________

Benefits of dissemination

17) Do you have any comments on the benefits of disseminating results of research to patients? __________

Further comments

18) Any further comments?
   ______________________________________

Finally some questions about yourself:

19) For which type of institution do you mainly work?
   - University
   - Private research centre
   - Public research centre
   - Hospital / health institution
   - Industry
   - Other (please specify): _______________

20) Where is your main country of work? ________________ (drop down list)

21) Approximately how many years have you been an active researcher? [Drop down list of numbers]

22) Please estimate the proportion of clinical trials with patients that you have been involved in where results were disseminated to participants? _________________
23) Please provide your email address if you would like to
  ☐ be entered into the prize draw
  ☐ receive the results of the survey

Please click on “submit” below to send us your responses.

Thank you for your help