Module 3: How to review research documents from a patient and public point of view

Learning outcomes

By the end of this module you should be able to do the following.

1. Recognise good practice in patient and public involvement (PPI).
2. Identify the strengths and weaknesses of the PPI described.
3. Make clear and realistic suggestions for improving PPI.

To help you achieve this, the module is split into two parts.

- Part A: Introduction to reviewing PPI in research documents.
- Part B: Questions to consider when reviewing research documents from a patient and public point of view.

Using this module

- This module is aimed at helping people new to PPI understand what to look for, but also aims to help those experienced at public reviewing (particularly funding committee members) add to their skills.

- If you are completely new to PPI and public reviewing, you may want to just download the checklist in ‘Further resources’ at the end of this module and dip into the module as you gain experience.

Part A: Introduction

Questions

In this module we look in detail at the type of questions to ask when reviewing a research document from a patient and public point of view. We will consider why we ask each question, and what good practice in PPI might be.

Below is an overview of the questions involved.

Why should this research be funded?

- Is the proposed research a priority?
- Is it important to patients and the public?
- Will it make a difference to people's lives?

How will the patients and public be involved?

- What are the proposed plans for PPI?
- Do the plans for PPI run throughout the research project life cycle?

Questions

Is there a separate, plain English summary which is clear and jargon-free?

Who is involved in the research ?

- Are the public contributors involved in the research the most appropriate people for the role?
- Does the research team have the right people?

Will the research study be able to recruit enough people to take part?

- How will people be recruited?
- Do arrangements for those taking part in the study (study participants) seem practical and fair?
- Would I be prepared to take part?

How will the PPI be managed?

- How will PPI be led and managed?
- Is there support and training in place for public contributors?
- Is the budget for the PPI adequate?

What to look for when reviewing

- This module describes good practice in PPI. It will help you to compare good practice in PPI with the planned PPI in the research documents you review.
- You can then give researchers feedback on the strengths of their plans and make suggestions on how to improve their PPI and project.
- Those offering you the review (for example, the researchers or a funder like us) will give you guidance on how to complete it. Answer as much as you can and don’t worry if there are questions you cannot answer.

What to look for when reviewing

- As you work through the research document you are reviewing, you may find it helpful to bear in mind some or all of the questions posed in the next section.
- Whether these questions are relevant will depend on the type of research document you are reviewing and the type of research study.
- A website link, where you will find guidance from our research programme funding centres, is listed in 'Further resources'.

Introducing ‘Pins or Plaster’: a research trial case study

We have included a fictional research application, the ‘**P**ins **o**r **P**laster’ (POP) trial, under the Resources tab.

You will be asked to review different aspects of this trial as you work through the questions.

You might find it helpful to read through the application before starting the next section.

Part B: The questions to consider when reviewing

1. Is the proposed research relevant and important to patients and the public?

Researchers, healthcare professionals, service providers, patients, carers and the public all have their own viewpoints and priorities.

Researcher focus

For example:

- How can I improve treatments, services and experiences for patients and service users?
- Can I build on my existing expertise and research in this field?
- How can I bring funding to my department?

Researchers, healthcare professionals, service providers, patients, carers and the public all have their own viewpoints and priorities.

Researcher focus

Healthcare professional and service provider focus

For example:

- Will it make treatment more effective?
- What burden does treating this condition place on NHS staff?
- Will it save the NHS money?

Researchers, healthcare professionals, service providers, patients, carers and the public all have their own viewpoints and priorities.

Researcher focus

Healthcare professional and service provider focus

Patient and public focus

For example:

- How are patients, carers and families affected by the condition?
- How can the research improve patients' quality of life?
- Do people with this condition support this research?

Researchers, healthcare professionals, service providers, patients, carers and the public all have their own viewpoints and priorities.

Researcher focus

Healthcare professional and service provider focus

Patient and public focus

Everybody has a different point of view on the research – we want to make sure the public voice is heard!

1. Is the proposed research relevant and important to patients and the public?

Is the proposed research worth doing?

Does the research provide value for money?

Are the right outcomes being measured?

1. Is the proposed research relevant and important to patients and the public?

1.1 Is the proposed research worth doing?

We are likely to have a different point of view to that of our researcher and health or social care colleagues. We should ask ourselves the following.

- Is this research something that will benefit or be a priority for people who experience this condition, service or treatment?
- Have patients or the public been involved in deciding and developing the research question?
- Will answering this question make a real difference to patients, service users or carers?

1. Is the proposed research relevant and important to patients and the public?

1.2 Does the research provide value for money?

- Will the research have a positive effect on enough patients or people to justify its cost?
- Is there a pressing need for the research to be done now?
- Is it clear from the research plan who or which groups (for example, healthcare planners, clinicians, patients or policy makers) are expected to benefit the most?
- As a public reviewer, you are not expected to assess whether the entire budget has been estimated correctly. However, you can comment on the following. a) Overall, does the research budget seem a reasonable investment of public money? b) Could it save health and social care costs in the long term?

1. Is the proposed research relevant and important to patients and the public?

1.3 Are the right outcomes being measured?

An outcome is something specific which is used to measure the effect of the research on people.

For example, health professionals may consider an eczema treatment outcome to be effective if it results in reduced areas of inflammation or reduced hospital admissions. But patients might put more value on reduced itching so they can comfortably sleep through the night or wear normal clothing.

Researchers are being encouraged to include Core Outcome Sets (COS) so that their research can easily be compared to or combined with other studies. Patients and the Public should have input into the development of these. For more information about COS see Further Resources at the end of this module

POP trial activity 1: Match the answer from the POP trial to the question. Then select the corresponding concern raised by the public reviewers.

Question	Answer	Reviewer concern
Have patients or the public been involved in deciding and developing the research question?	A ‘POP study’ tent was set up to get the views of families and children.	The public were not consulted about the importance of the research question itself.
Will answering this question make a real difference to patients, service users and carers?	Existing research reveals a clear lack of evidence on whether casts or surgery are better for patients.	It’s not clear why surgeons don’t follow current NICE guidelines, or what their approach would be if casts are shown to have better results than surgery.
Will the research have a positive effect on a significant number of patients?	6300 children aged 8 to 12 go to A&E each year with fractures to the bones in their arms.	It is not clear if 6300 is a ‘significant’ number – it would be more helpful given as a percentage of children in this age bracket.
Could it save health and social care costs?	If a cast is found to be more effective, it is significantly cheaper than surgery.	It would be helpful to know the total current cost to the NHS, and potential savings.
Are the right outcomes being measured?	Questionnaire answers showed that full recovery was the most important factor for families.	The focus on long-term outcomes does not consider the child’s quality of life during treatment.

2. Is there a separate, easy-to-read plain English summary?

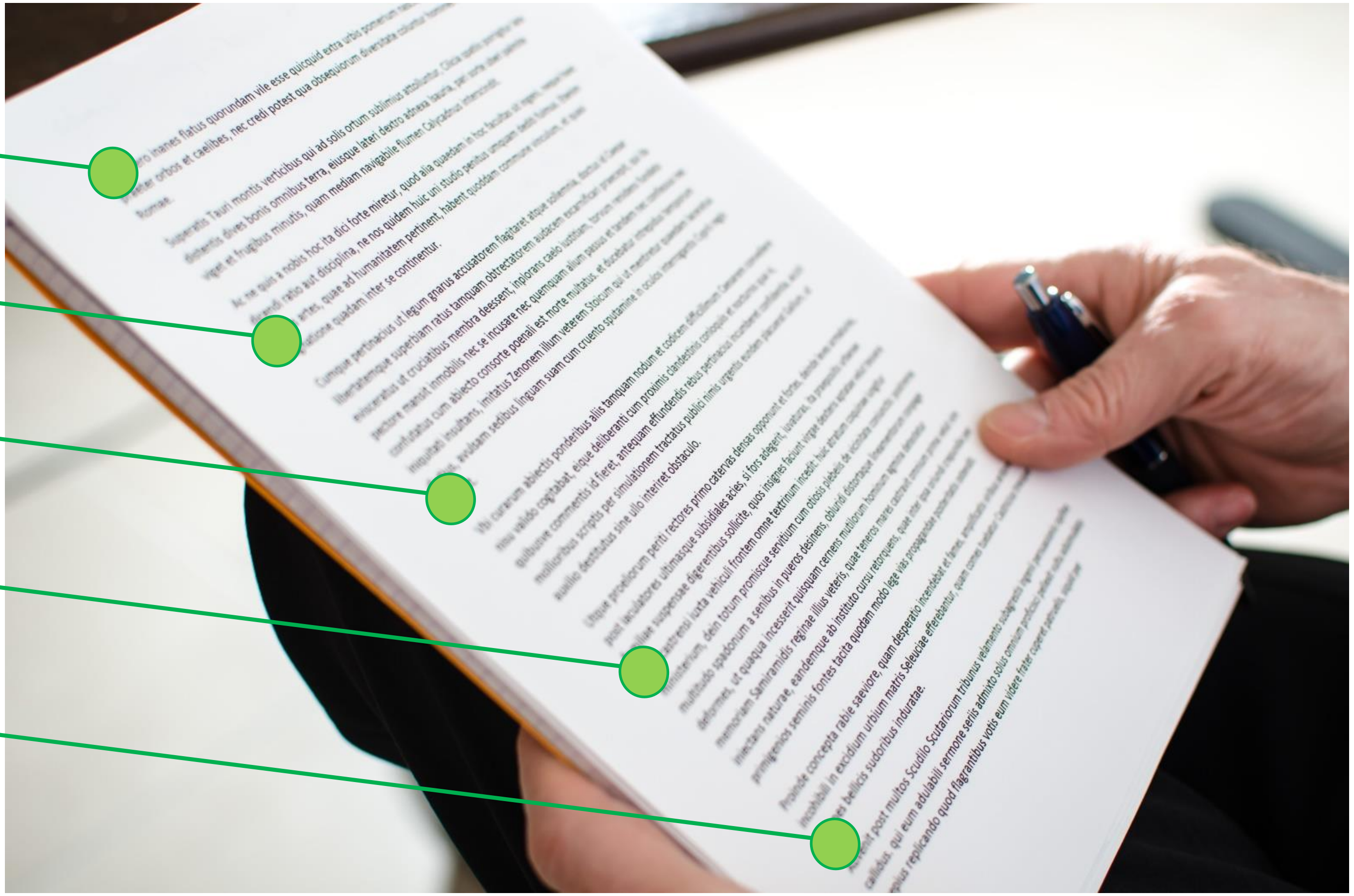
Definition of a plain English summary (PES):

“It is a clear, easy-to-read summary that is as jargon-free as possible. It provides an overview of the whole research study, that readers can understand the **first time** they read it.”

INVOLVE Jargon Buster

As well as being part of an overall plan, the PES needs to stand alone as a useful overview of a study.

2. Is there a separate, easy-to-read plain English summary?



Content

Format

Readability

Use of language

Ready for future use

2. Is there a separate, easy-to-read plain English summary?

2.1 Content

Does the PES include the relevant content recommended by us (NIHR)? It should include:

- aims and background to provide clear reasons for the research
- the design and methods used
- the proposed patient and public involvement, and
- plans for sharing the results (known as dissemination).

2. Is there a separate, easy-to-read plain English summary?

2.2 Format

- Is the format and layout clear, with effective use of headings, bullet points and white space?
- Suitable headings might include The issue, Our aims and plans, Involving the public, Sharing our findings, and Impact.

2.3 Readability

- Are the sentences short?
- Does the structure flow and make sense?
- Is the language used appropriate and clear? If not, where are the problems?
- Are abbreviations and technical words kept to a minimum?

2. Is there a separate, easy-to-read plain English summary?

2.4 Use of language

- Is the PES free from jargon?
- Are any scientific terms, abbreviations and jargon explained? If not, which terms need explanation?

2.5 Ready for future use - If this research is funded, the plain English summary will be published alone on a variety of websites.

- Could this plain English summary be used on its own to describe the proposed research? If not, what further information is needed?

POP trial activity 2

Read through the plain English summary at the end of the POP trial.

1) In your opinion, are the following statements true or false?

a) Content: The PES does not mention the PPI.

b) Format: The PES is well-structured.

c) Readability: The PES is written in an over-complicated style.

2) Use of language: ‘Prospective superiority trial’ is explained, but are there other terms used that might be considered jargon? List any below.

Suggested answers

1a) False. The involvement of Tom, his mum and other families and children is described, although reviewers felt that more explanation of the Family Study Advisory Board would be helpful.

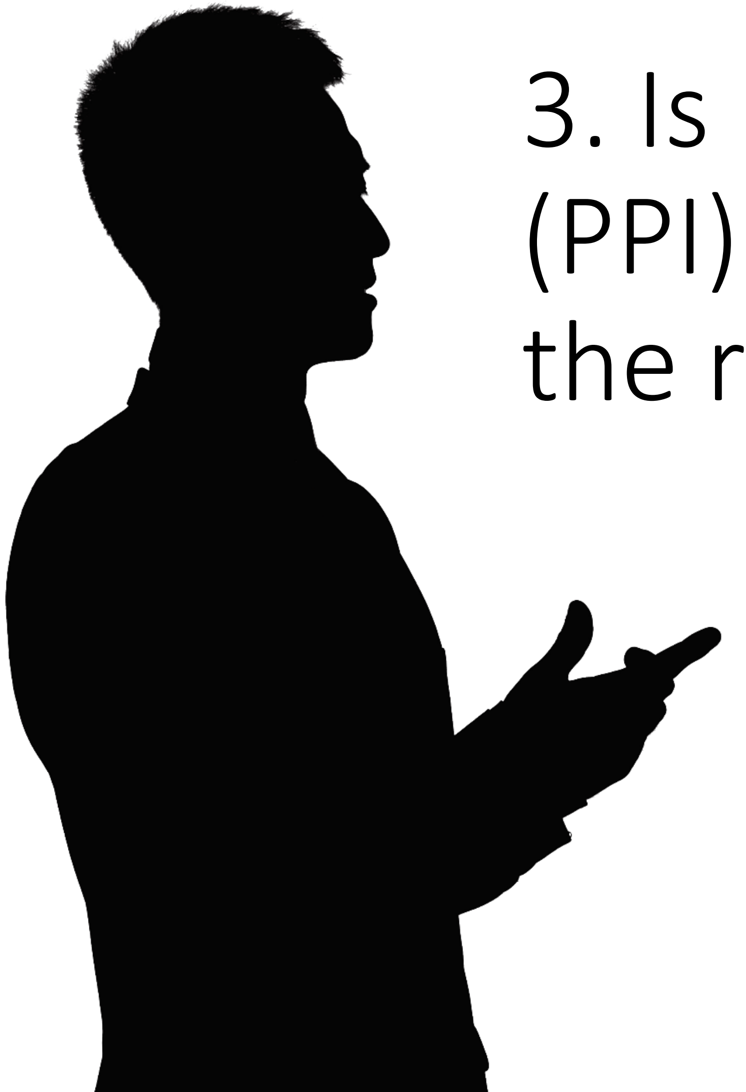
1b) True. Reviewers appreciated the way headings had been used to break up sections.

1c) False. Reviewers felt it was clear and easy to read, with short sentences.

2) Some terms reviewers highlighted were:

A&E Analyse data Restoring full function

HES Randomly allocated Service users



3. Is patient and public involvement (PPI) planned at appropriate points in the research project life cycle?

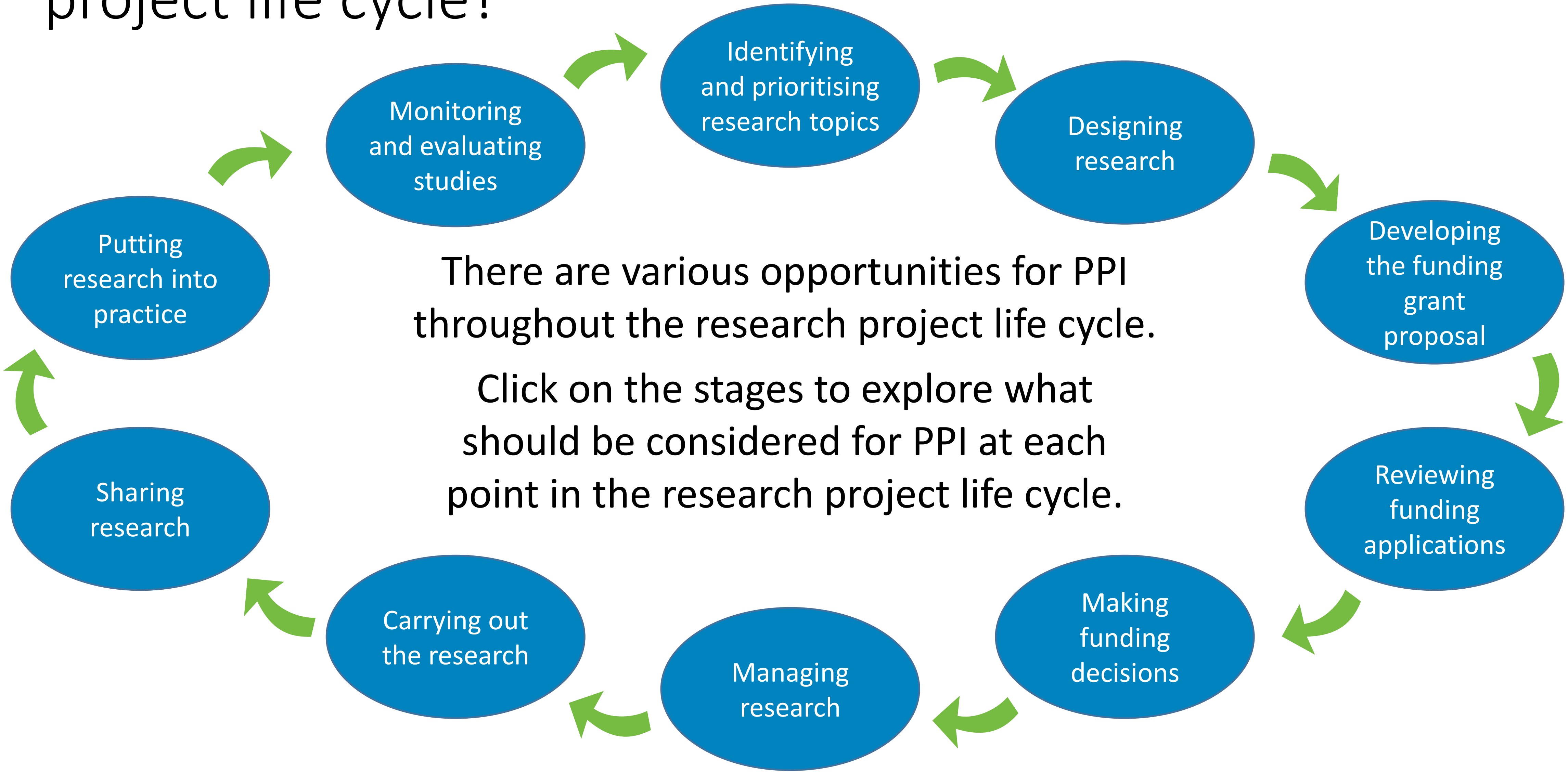
3. Is patient and public involvement (PPI) **planned at appropriate points in the research project life cycle?**

- Are the proposed PPI plans appropriate and adequate?
- Can you identify particular strengths and weaknesses, and areas that could be improved?
- If there is no PPI in the research document, is there a good reason?

Is patient and public involvement (PPI) planned at appropriate points in the research project life cycle?

- We will now describe how members of the public can be involved in the research project life cycle. Whether the PPI plans are appropriate depends on the topic being studied and its design and size.
- As described in module 2, there is a variety of ways the public can be involved throughout the research life cycle. The following slides help you assess the type and level of PPI.

3. Is PPI planned at appropriate points in the research project life cycle?



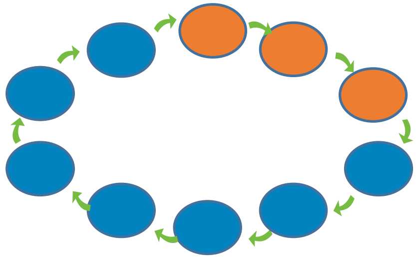
There are various opportunities for PPI throughout the research project life cycle.

Click on the stages to explore what should be considered for PPI at each point in the research project life cycle.

3. Is PPI planned at appropriate points in the research project life cycle?

3.1 What has happened so far?

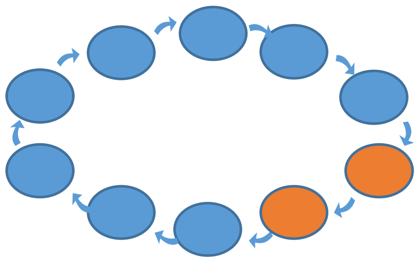
- What has the PPI been like so far in shaping and developing the research document?
- If the public, patients and carers have already been involved, do you think it has made a difference? Or does it feel like the researchers were just ‘ticking the box’? (‘Ticking the box’ could include statements like, ‘We talked to a couple of patients. They liked the study.’)
- Were the public involved in identifying and prioritising the research questions, designing the study and developing the research plan? If so, how?



3. Is PPI planned at appropriate points in the research project life cycle?

3.2 What is happening now?

- Your role is to review the funding application from a patient and public point of view.
- Your review will guide the decision about whether the research is funded.



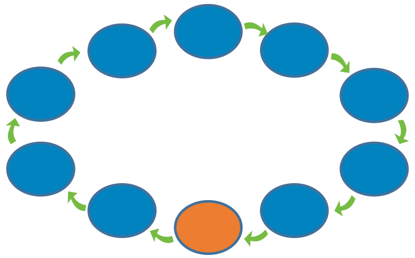
3. Is PPI planned at appropriate points in the research project life cycle?

3.3 Managing research

Public contributors can sit on management groups, advisory groups or steering committees which manage or oversee the running of a research study.

They help to make sure:

- a public point of view is included
- those taking part in the study (study participants) are treated fairly and ethically
- public involvement in the project is properly budgeted for and PPI funds are used for their intended purpose
- there is effective support for public contributors
- advice is provided on what is practical for those taking part in the study, and
- the public are involved in recruiting staff and researchers.

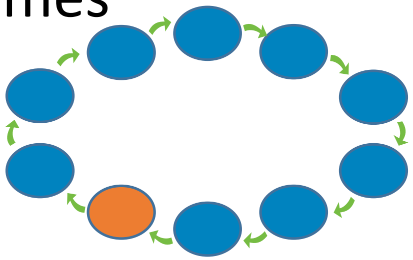


3. Is PPI planned at appropriate points in the research project life cycle?

3.4 Carrying out research

Members of the public may be collaborators or co-applicants and so part of the research team. Look for ways they are or could be involved in carrying out the research, such as:

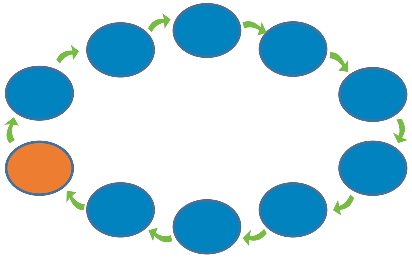
- contributing to the design of the research
- producing research updates that are easy to follow
- helping with ways to recruit more people to take part in the study
- carrying out research interviews and surveys and being involved with focus groups
- contributing to analysing data and writing up findings, and
- helping to write patient information leaflets and consent forms, sometimes called ‘patient-facing materials’.



3. Is PPI planned at appropriate points in the research project life cycle?

3.5 Sharing research (known as dissemination)

- Are the following included in plans to share the findings, as well as researchers and health and social care professionals?
  - Those taking part in the study (study participants)
  - Affected patient groups
  - Advocacy or campaigning charities
  - General public and the media
- What methods for sharing the findings have been planned? Can they be more creative, for example use videos to tell patient stories or use social media?
- Have the researchers shown how the research could have an impact on health and social care practice? For example, introduction of national guidelines, change in clinical practice or service delivery, or a need for further research.



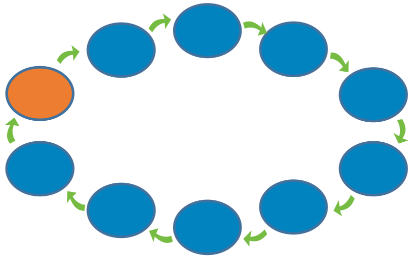
3. Is PPI planned at appropriate points in the research project life cycle?

3.6 Putting research into practice (known as implementation)

Involving the public in putting the research findings into practice may help to make any suggested changes more acceptable.

In the past, implementation plans have not been included in many research documents. This is changing… look for ways the public are or could be involved in a variety of roles, such as:

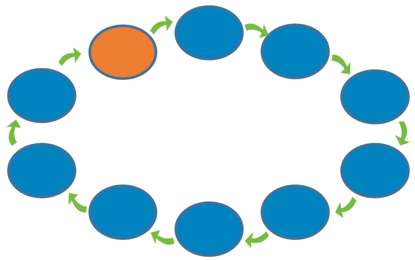
- helping to write the document which will explain how a new treatment will be delivered to patients, and
- developing patient information for new services or care within hospitals, doctors' surgeries and so on.



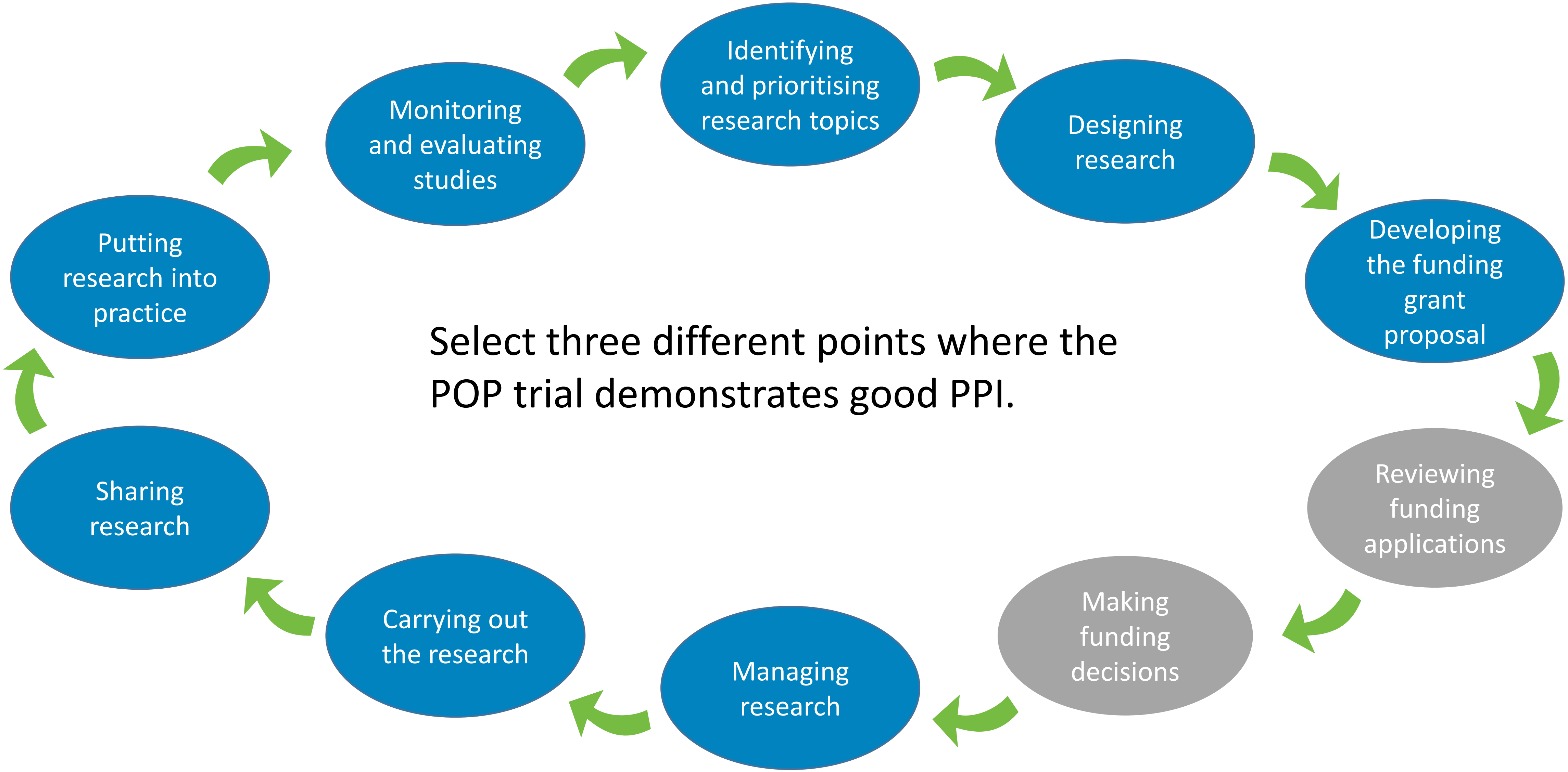
3. Is PPI planned at appropriate points in the research project life cycle?

3.7 Monitoring and evaluating studies

- Monitoring and evaluating PPI is becoming more common.
- Ask yourself if the effect (impact) of PPI, and its contribution, will be evaluated throughout the study. This information could help improve future PPI.
- There are frameworks for reporting and evaluating PPI. You can find links to these in the ‘Further resources’ section.
- Will the public contributors together with researchers evaluate the whole research process? What went well? What didn’t?
- Will public contributors have the opportunity to reflect on their role in the research and what they have learnt?



POP trial activity 3



Identifying and prioritising research topics

Designing research

Developing the funding grant proposal

Reviewing funding applications

Making funding decisions

Managing research

Carrying out the research

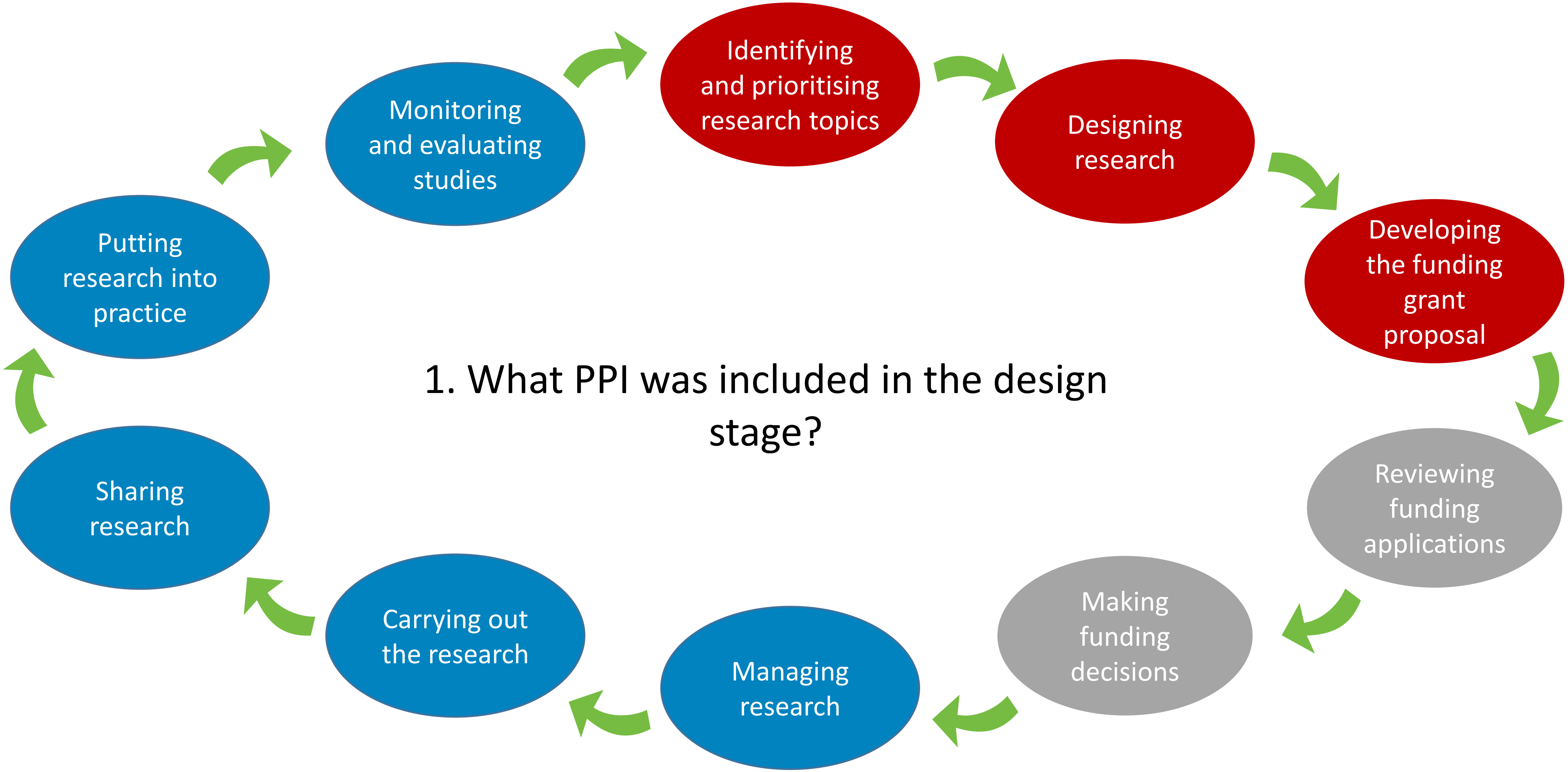
Sharing research

Putting research into practice

Monitoring and evaluating studies

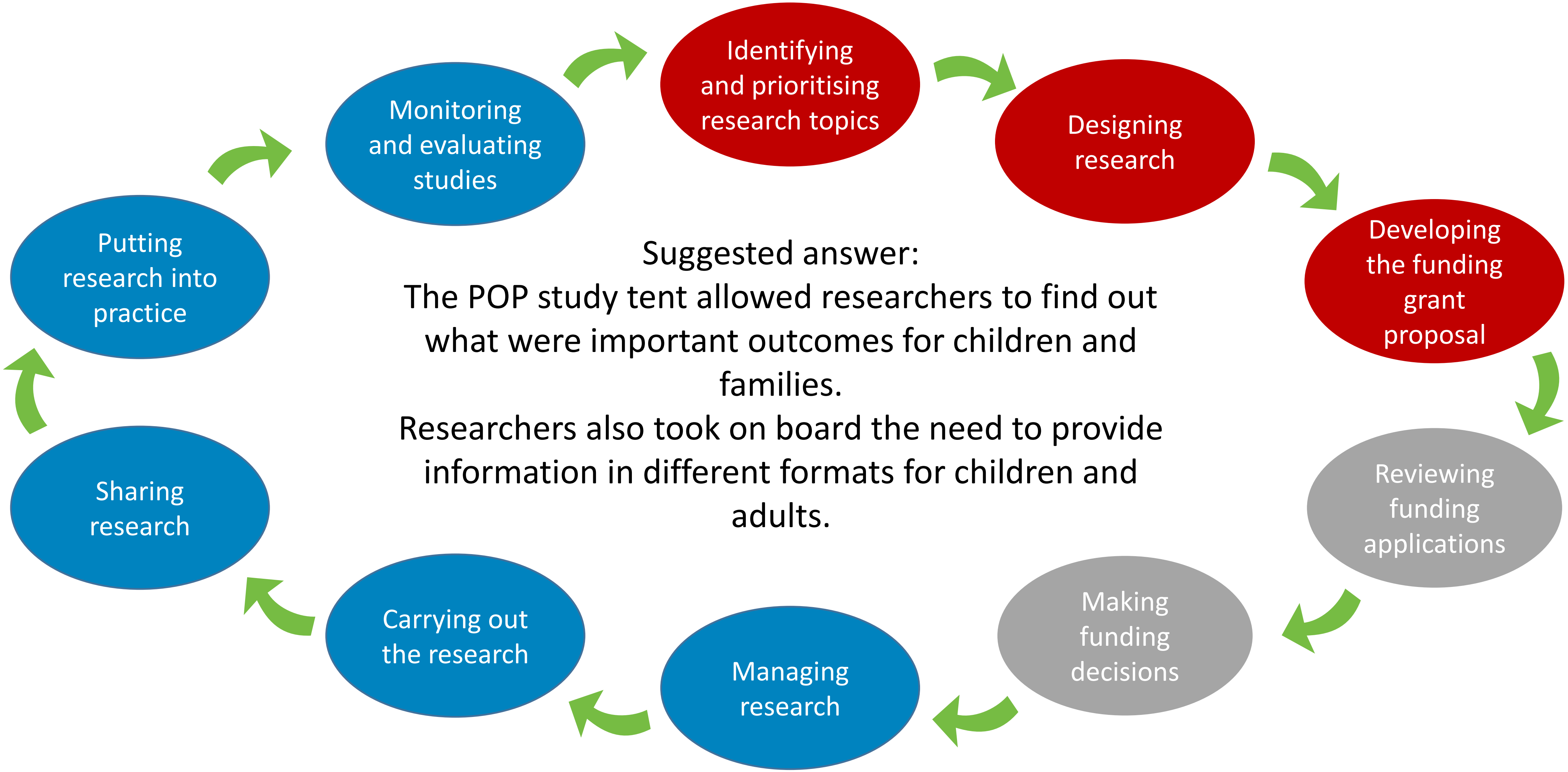
Select three different points where the POP trial demonstrates good PPI.

POP trial activity 3



1. What PPI was included in the design stage?

POP trial activity 3



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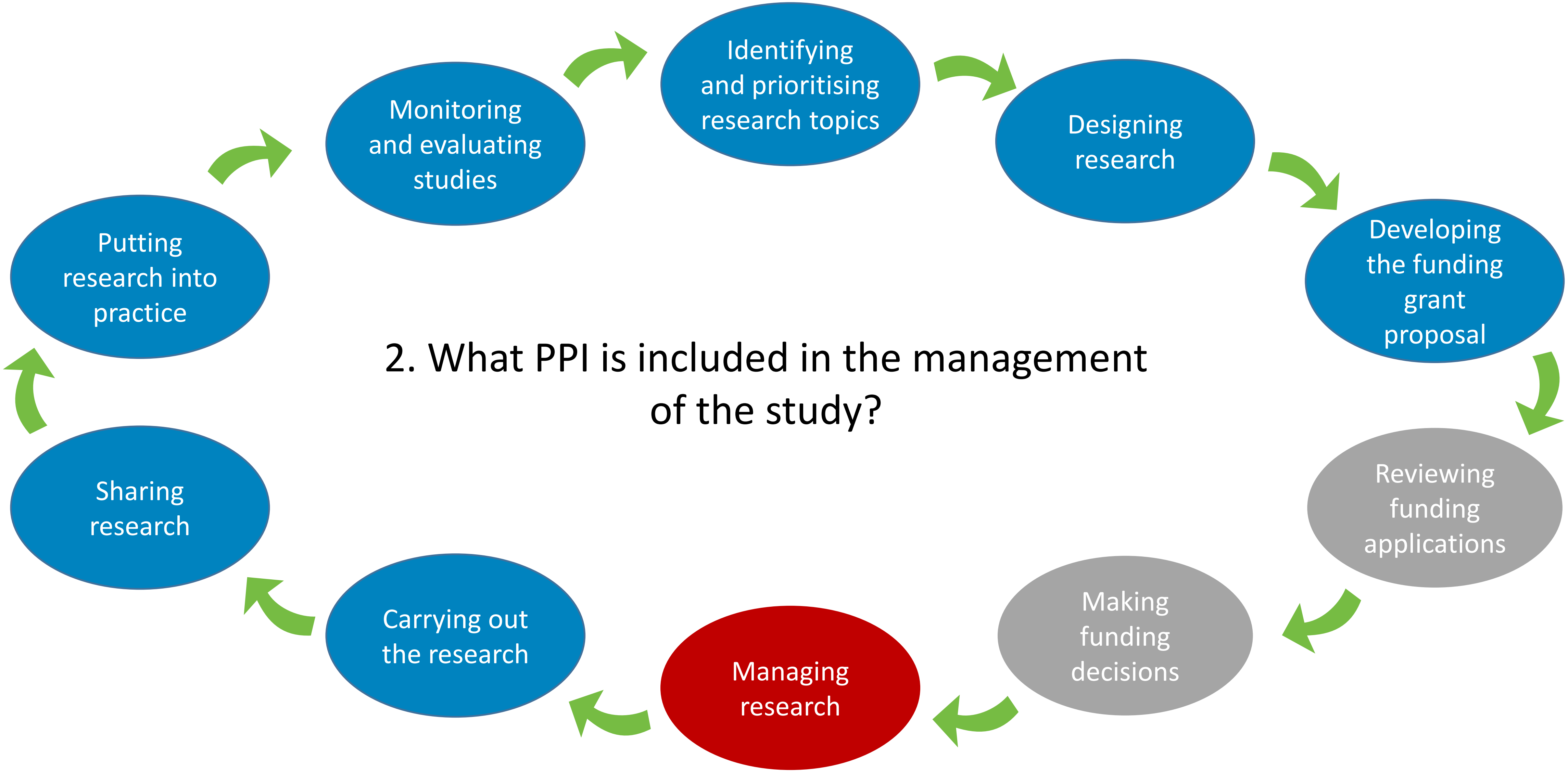
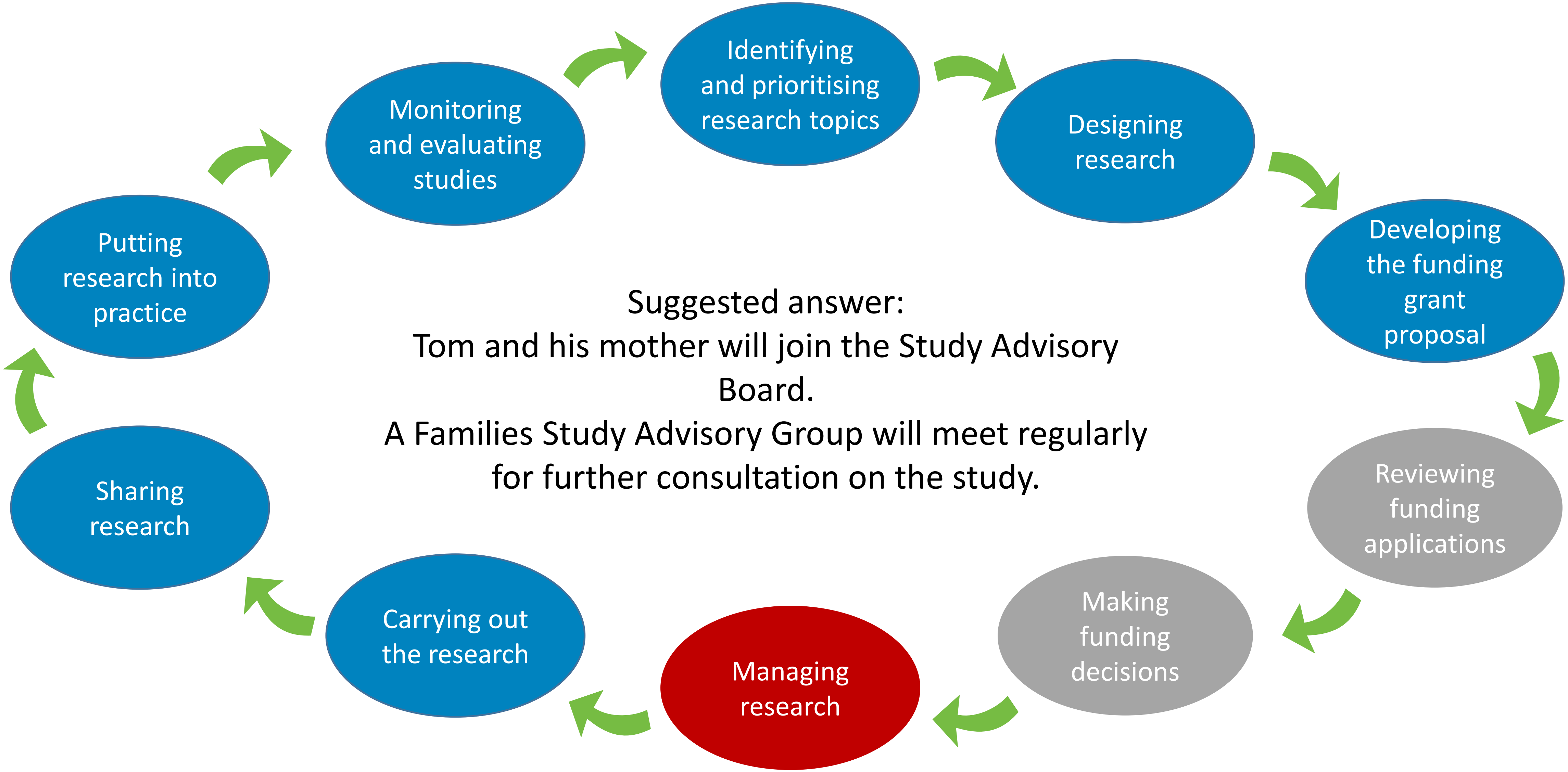
Suggested answer:
The POP study tent allowed researchers to find out what were important outcomes for children and families.
Researchers also took on board the need to provide information in different formats for children and adults.

POP trial activity 3



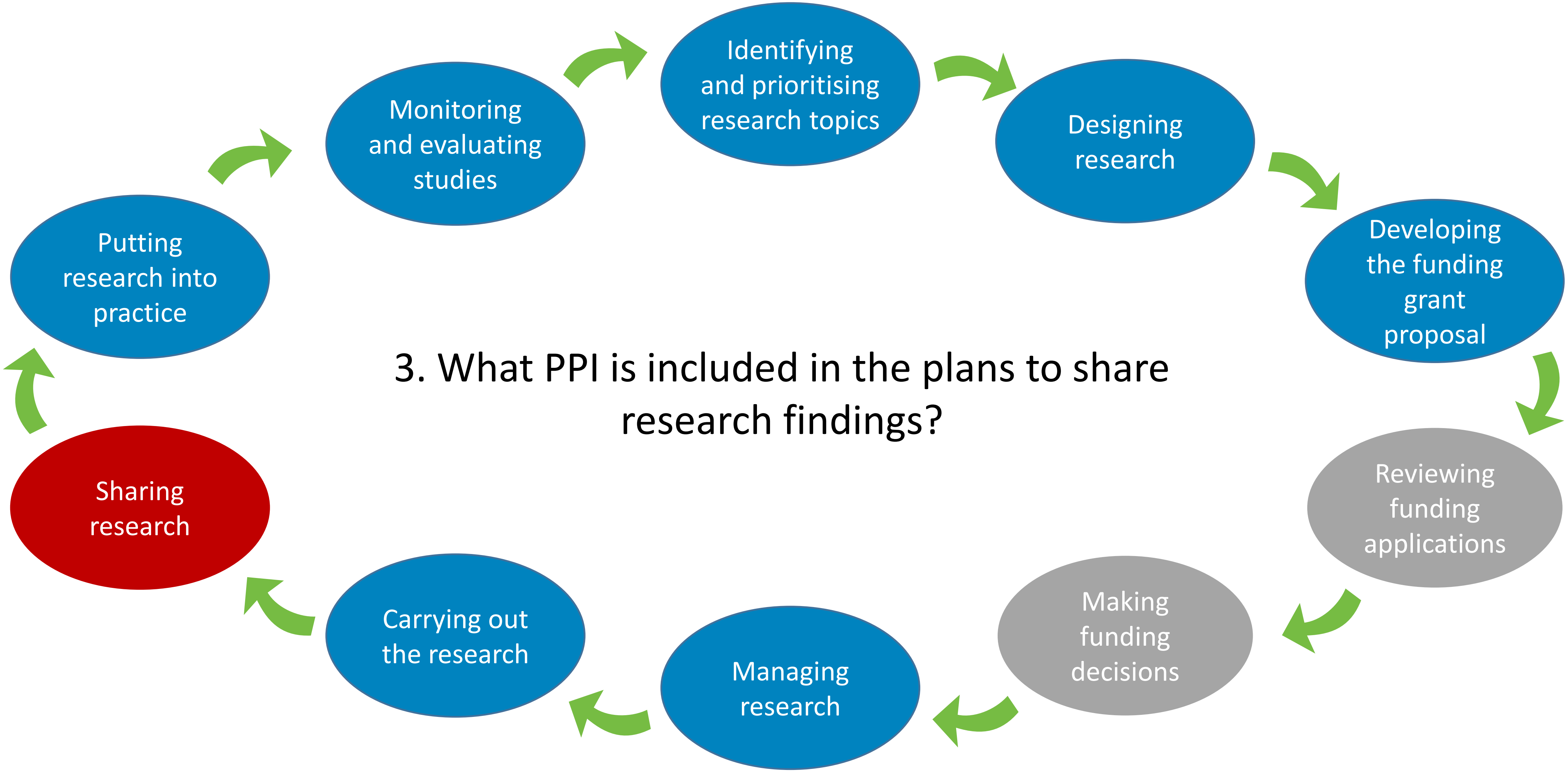
2. What PPI is included in the management of the study?

POP trial activity 3



Suggested answer:
Tom and his mother will join the Study Advisory Board.
A Families Study Advisory Group will meet regularly for further consultation on the study.

POP trial activity 3



Identifying and prioritising research topics

Designing research

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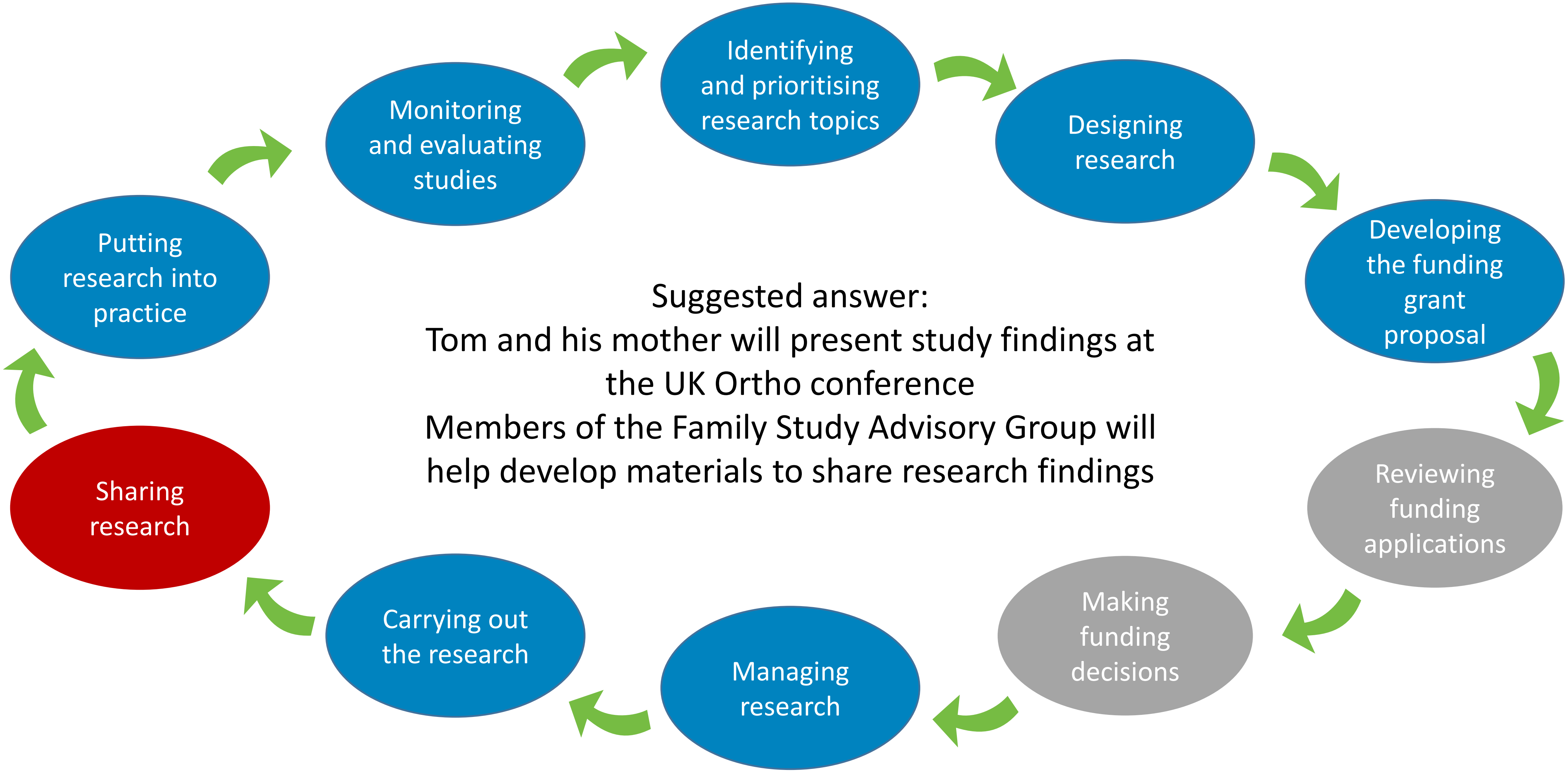
Sharing research

Putting research into practice

Monitoring and evaluating studies

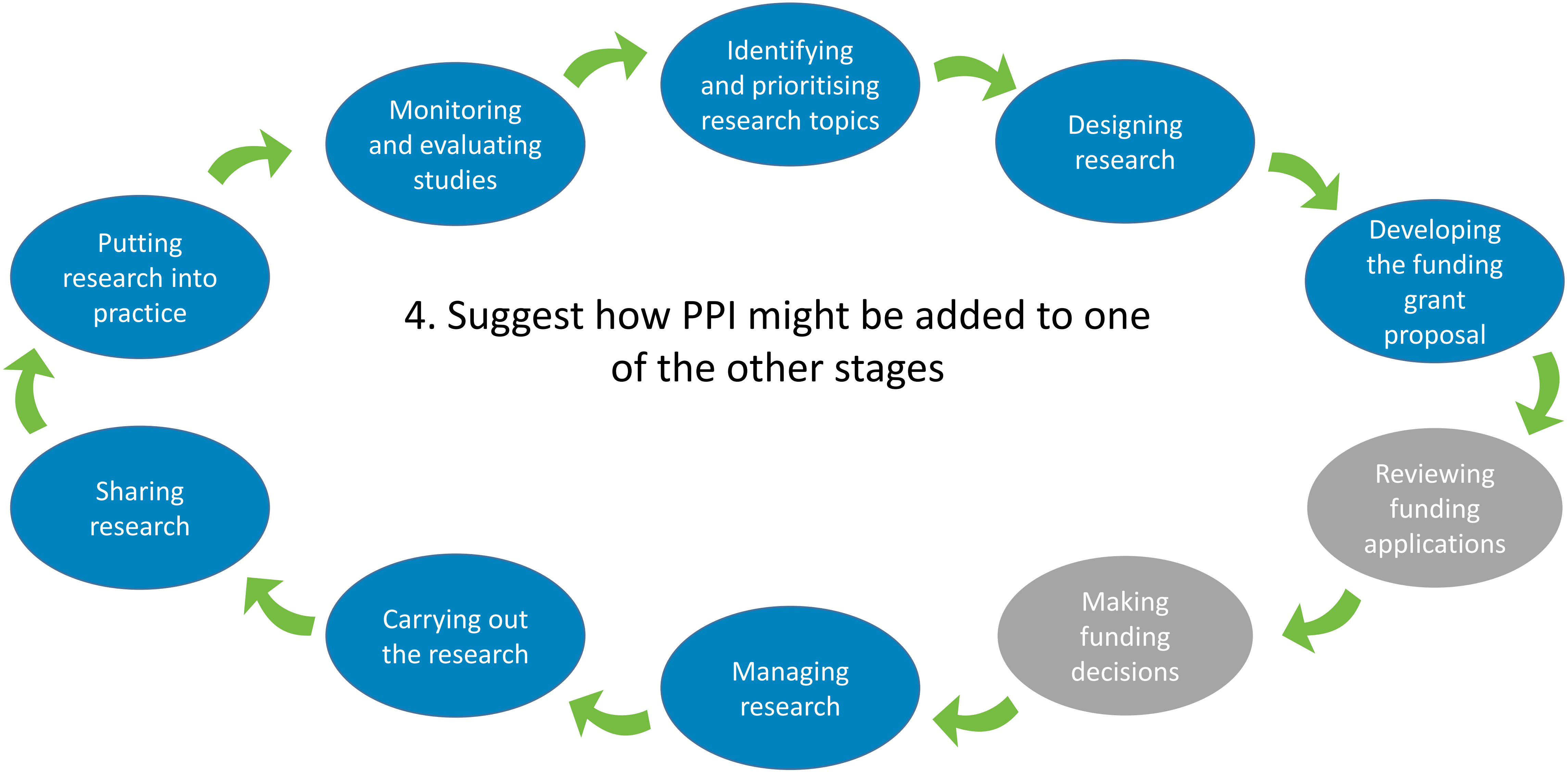
3. What PPI is included in the plans to share research findings?

POP trial activity 3



Suggested answer:
Tom and his mother will present study findings at the UK Ortho conference
Members of the Family Study Advisory Group will help develop materials to share research findings

POP trial activity 3



Identifying and prioritising research topics

Designing research

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4. Suggest how PPI might be added to one of the other stages

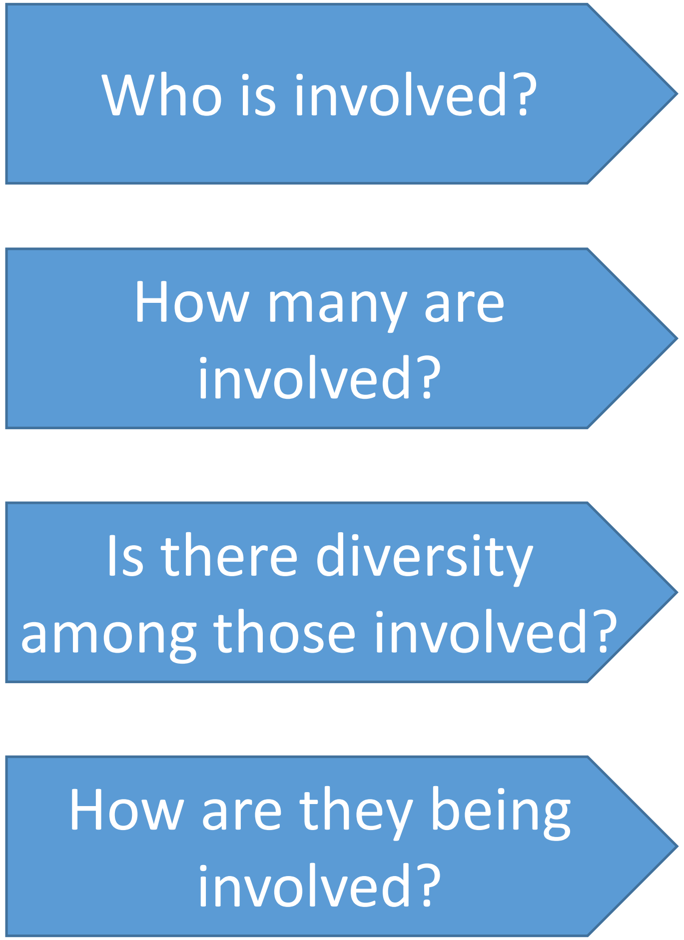
4. Are members of the public involved in a useful way and are they the right people?

Different experiences

Public contributors have different and unique:

- experiences as a patient
- cultural, social, economic and ethnic backgrounds
- experiences of caring
- work and career backgrounds
- experience of PPI in research
- networks and contacts with patients, support groups and charities, and
- skills (for example, writing, public speaking, project management, financial, data analysis and so on).

4. Are members of the public involved in a useful way and are they the most appropriate people?



Who is involved?

How many are involved?

Is there diversity among those involved?

How are they being involved?

4. Are members of the public involved in a useful way and are they the most appropriate people?

4.1 Who is involved?

- Are the public contributors believable, trustworthy and appropriate? For example, do they have relevant personal experience?
- Do the reasons for choosing the public contributors seem appropriate?
- Is there the right mix? For example, parent, carer, patient, child, service user.
- Charity employees could be listed as public contributors. They bring valuable expertise and can add another viewpoint but should be included in addition to patients, carers and service users who have first-hand experience.

4. Are members of the public involved in a useful way and are they the most appropriate people?

4.2 How many are involved?

- Are there enough public contributors for the roles they are expected to carry out?
- Involving more than one or two people allows:
  - different viewpoints
  - more skills and experience
  - opportunities to support and learn from each other
  - a better balance of responsibility in meetings with senior health professionals and academics
  - for unexpected absences, and
  - for people dropping out over the project life cycle. Research projects can run for several years!

4. Are members of the public involved in a useful way and are they the most appropriate people?

4.3 Is there diversity among those involved?

- How have the researchers made sure they are involving a diverse group of people? Do the public contributors reflect the people the research is about? This diversity might include race and ethnic background, culture and belief, gender and sexuality, age and social status, ability and people’s use of health and social care services.
- Have the researchers considered how they will help public contributors to be fully and equally involved? For example, convenient meeting locations and times, support for carers, fully accessible meeting places, information in different formats and languages and so on.

4. Are members of the public involved in a useful way and are they the most appropriate people?

4.4 How are they involved?

- As well as being involved in different stages of the research life cycle, the public take on different roles in the research team. For example, co-applicant, collaborator, co-producer, advisory team member, management, steering or review group member.
- Ways of carrying out PPI in research and the public contributor roles vary greatly depending on the type of study design, the experience of the researchers and the topic being researched.
- We outline ways of involving patients and the public in research in the next slide.

Ways of being involved

Some of the different ways of involving patients and the public in research are listed below. Select the term from the drop-down list that matches each definition.

Consultation	When researchers ask members of the public for their views and may or may not use these views to guide their decision-making.
Collaboration	An ongoing partnership between researchers and the members of the public they are working with, where decisions about the research are shared.
Co-production	When researchers, practitioners and the public work together, sharing responsibility. There is an assumption that those affected by research are the best people to design and deliver it and have skills and knowledge of equal importance. But relationships must be valued and nurtured, and efforts made to share responsibility. People should be supported and helped to realise their potential in carrying out their roles and responsibilities in the project.
User-controlled research	Research that is actively controlled, directed and managed by service users and their organisations.
User-led research	Research that is led and shaped by service users but is not necessarily controlled or carried out by them.

POP trial activity 4

Read through the POP trial and answer the following questions.

1. Which of these four questions is **not** covered in the research application?

a) Who is involved?
b) How many people are involved?
c) Is there diversity among those involved?
d) How are they involved?

Answer: iii. Is there diversity among those involved?

POP trial activity 4

2. How is Tom's mum involved?

a) She's there to support Tom
b) She's there as a representative of the UK Kids Broken Bones Forum
c) She's there as a parent representative
d) All of the above

Answer: There isn't necessarily a right answer to this! Tom's mum (Sonia Lambert) is listed as a 'parent representative' in the list of co-applicants. Her experience with the charity gives another point of view, but she is there as a parent, so it would be better to have an additional member to represent the charity.

5. Does the research team have the right people?

5. Does the research team have the right people?

- Does the research team appear to have the right mix of skills and knowledge to carry out this research? Do they have a track record in this area?
- Are patients, service users or carers included as co-applicants in the research team? If they are, is it clear what their role will be and what they will bring to the research team?

For example, if the research topic involves a treatment that nurses give, is there a nurse on the team? If the research is based in the community (primary care) is there a family doctor (GP) involved or other appropriate professionals such as pharmacists, social workers, community nurses or care-home staff?

POP trial activity 5

1. Are the following areas of expertise covered by the research team? (Answer yes or no.)

a) Surgery

b) Applying casts

c) Physiotherapy (physiotherapists help people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice)

d) Paediatrics (medicine involving the care of infants, children and adolescents)

2. Tom and his mum are listed as co-applicants. Is it clear what their roles will be?

a) Yes

b) Partly

c) No

Suggested answers

1. Are the following areas of expertise covered by the research team?

a) Surgery Yes

b) Applying casts Yes

c) Physiotherapy No – this would be valuable to add, as getting broken bones working properly again was identified as the key outcome

d) Paediatrics Yes

2. Tom and his mum are listed as co-applicants. Is it clear what their roles will be?

b) Partly – it says they will be part of the Study Advisory Group and will help present findings at a conference. More detail would be helpful. What will their roles and activities be, and how will Tom's role (as a child) differ from his mum's?

6. Is the planned PPI being managed well?

6. Is the planned PPI being managed well?

This covers how both the public involvement activities and the public contributors are managed.

Are there support, training, communication and feedback plans for public contributors in place?

Is there a clear and accountable leadership for PPI in place?

INVOLVE (our national advisory group) has produced national standards for public involvement in research. There is a link to these standards in ‘Further resources’ at the end of this module.

6. Is the planned PPI being managed well?

6.1 Support, training and feedback for public contributors

- What training and support is provided for public contributors in the research plan (for example, for recruitment, induction and training)?
- Who will manage the public contributors, including organising their payments, travel, and support for carers and dependants?
- Do the researchers recognise their duty of care to public contributors, especially contributors' emotional needs and their right to withdraw at any time?
- What are the arrangements for study communications and feeding back to the public contributors involved in the project on progress and other wider project issues?

6. Is the planned PPI being managed well?

6.2 Leadership for PPI

- Is there a named person on the research team who will have overall responsibility for PPI? Who will provide or organise support and training for public contributors?
- Is there a plan in place to manage the public involvement? How will it be monitored and refined?
- Sometimes research teams ‘buy in’ PPI leadership from another organisation such as a local PPI lead for an institution (university or hospital trust) or charity. This may be fine, but consider the following.
  - What if this funding is withdrawn?
  - Does this mean the research team do not value PPI or is this a way of looking for PPI expertise which they lack?

POP trial activity 6

1. Which aspects of the application show the planned PPI is being managed well?

2. What aspects might the research team need to consider further, in order to manage the PPI appropriately?

Suggested answer

1. There is good support planned, including a ‘buddy’ on the research team who will provide support both before and between meetings. A named team member is responsible for supporting, training and managing PPI members (public contributors).
2. Tom and his mother are being asked to make quite a commitment to the study, both in time and in responsibility for contributions. Could another public adult and child member be found to add support and widen the experience? How will meetings be made accessible to Tom and the children involved in the Family Study Advisory Group? How will the Study Advisory Board and Family Study Advisory Group communicate with each other?

7. Is the budget for the proposed PPI adequate?

7. Is the budget for the proposed PPI adequate?

7.1 Is there a budget for the PPI? Does it seem enough to you? Why do you think that?

Some public reviewers suggest exploring further if the PPI budget is less than 2% of the whole study costs.

All the great PPI described in the research plan will be impossible if there is no budget to carry out the activities described.

7. Is the budget for the proposed PPI adequate?

7.2 Have all the PPI activities been estimated for, using INVOLVE guidelines?

- Costs might include recruiting, inducting and training public contributors, PPI activities described in the research plan, public membership on project review, advisory or steering groups, and activities involved in sharing the research findings (dissemination).
- Have expenses such as travel, accommodation, meals, drinks and dependants' and carers' costs been accounted for?

POP trial activity 7

In this research document there is no information about estimating costs. A full research application or proposal (known as a stage 2 application in the NIHR) will have a breakdown of costs.

Instead, you might want to explore the tools listed below, which you can find in ‘Further resources’.

- INVOLVE has a cost calculator to help researchers work out their PPI costs.
- We have also developed a PPI activity planner which can help you break down the activities and help you to estimate costs.

8. Do arrangements for the people taking part in the study seem practical and fair?

8. Do arrangements for the people taking part in the study seem practical and fair?

- Are the research plans for those taking part (study participants) practical, fair, realistic and not too much of a burden? Do you have any concerns about people's safety and well-being and their ability to access the study?
- Do you think there are things that would stop people taking part in the research? Do you think the researchers understand the needs of the patient group well enough?
- Why might people not want to take part in the research? How would you feel if you or a member of your family were asked to take part? (If people don't want to take part in the study, it won't get anywhere.)

8. Do arrangements for the people taking part in the study seem practical and fair?

- What changes should be made to make the research more accessible for people taking part in it?
- How could people be supported (for example, through helplines, a named contact, or other services)?
- Do the families and carers of those taking part need more information and support?
- If those taking part are asked to keep diaries or fill in questionnaires, could they do it online, by a voice recording or on a mobile phone?
- How are they going to get to clinic appointments or interviews the researchers want them to attend?

What might be the common barriers for people who are invited to take part in a study? Consider the topics and groups below, then click for some suggestions.

Access

People with disabilities

Parents

Recently bereaved

Older people

Cultural

People who work

Carers

Non-English speakers

Children

- **Access –** parking, travelling distance, method of transport and how often they need to attend.
- **Parents –** childcare, school holidays, travelling with small children or babies.
- **Older people –** travel, hearing, mobility, memory problems, winter or cold weather.
- **People who work –** time off work, number of appointments, time of day.
- **Carers –** caring responsibilities.
- **Non-English speakers –** language, reading.
- **Children –** carer support needed, school days, travel, level of language and understanding.
- **Cultural** – cultural beliefs, routines and restrictions, traditional or holistic medicines (such as Chinese medicine, homeopathy and complementary therapies) as opposed to current medicine (as provided by Western doctors).
- **Recently bereaved people –** time since the bereavement and their level of coping.
- **People with disabilities** – access issues such as travel, parking, lifts, mobility, hearing, sight, learning difficulties.

POP trial activity 8

The methods for collecting information from those taking part in the study are described in the plain English summary.

Identify any areas of concern or questions you might have about these arrangements.

Suggested answer

Some areas other reviewers highlighted included the following.

- Four questionnaires at the time of the injury and then at three, six and 12 months is a lot for people to manage. Would three be enough?
- How will the questionnaires be distributed? Online or by post?
- Will parents or children fill in the questionnaires? It is not clear.
- Will questionnaires be available in other languages if needed?

You may have thought of some others.

How would you rate the PPI in the POP trial?

☆ ☆ ☆ ☆ ☆

Overall, public reviewers felt that this was a very good PPI proposal.

It included imaginative use of PPI focused on the patient and their parents.

PPI was firmly incorporated throughout the research process.

Download the comments in full here.

Hear from our public reviewers

To finish, you might like to watch the videos below, in which public reviewers share their experiences.

- Key things we look for when reviewing: https://youtu.be/24IxWZHuBHY
- Why are you involved in reviewing? https://youtu.be/4iDaTjdEtCc
- What this course provides: https://youtu.be/F-XGwG14cl4

Congratulations!

- You have completed the module.
- Hopefully, you now feel familiar with some of the questions to ask when reviewing research documents from a patient and public point of view.
- Remember, you can always come back and dip in and out of the course as your learning needs change and develop.

Further resources

Reviewing research documents

- How to review a research application, East Midlands Academic Health Science Network. http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How_to_review_a_health_research_application.pdf
- Simon Denegri's Lay Review. Part II of "How to be a lay reviewer of health research:" Being on a scientific review panel. Simon Denegri, NIHR National Director for Patients and Public in Research. https://simondenegri.com/2014/10/14/part-ii-of-how-to-be-a-lay-reviewer-of-health-research-being-on-a-scientific-review-panel/
- Simon Denegri, The art of lay reviewing in health research: some pointers. https://simondenegri.com/2014/10/03/the-art-of-lay-reviewing-in-health-research-some-pointers/
- Wright et al., 2010 Critical appraisal guidelines for assessing the quality and impact of user involvement in research. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060547/
- NIHR guidance for reviewing research applications. https://www.nihr.ac.uk/patients-and-public/how-to-join-in/become-a-reviewer/public-reviewing-whats-involved.htm
- Top tips for reviewing research applications. http://www.invo.org.uk/wp-content/uploads/2018/01/Top-Tips-2-Reviewing-Research-Applications-v1.pdf

Further resources continued

What is good practice in PPI?

- National Standards for Public Involvement in Research. https://sites.google.com/nihr.ac.uk/pi-standards/home
- Briefing Notes for Researchers which provide guidance on methods and good practice on involving the public in research. http://www.invo.org.uk/resource-centre/resource-for-researchers/
- Videos where people describe their PPI activities. http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/what-activities-and-tasks-are-involved
- What makes good public involvement in research? http://www.invo.org.uk/wp-content/uploads/2018/01/Top-Tips-1-What-makes-good-public-involvement-v1.pdf
- How can public involvement strengthen research? http://www.invo.org.uk/wp-content/uploads/2018/01/Top-Tips-4-PPI-improving-research-v1.pdf
- How to engage seldom heard groups. http://emahsn.org.uk/images/resource-hub/PPI%20documents/How%20to%20guidance/How_to_engage_seldom_heard_groups.pdf

Further resources continued

Plain English summaries

- INVOLVE Make it Clear. http://www.invo.org.uk/makeitclear
- Peninsula Cerebra Research Unit for Childhood Disability Research (PenCRU) write their Plain language summaries with parents of disabled children from their Family Faculty. www.pencru.org/projectsmeetings/plain_language_summaries/
- Plain English Campaign. http://www.plainenglish.co.uk/free-guides.html

Core Outcome Sets

- COMET core outcome set Plain Language summary: http://www.comet-initiative.org/assets/downloads/COMET%20Plain%20Language%20Summary%20v4.pdf
- COMET core outcome set animation: http://www.comet-initiative.org/resources/PlainLanguageSummary
- COMET webinar “No Choice of Outcomes About Us Without Us”: http://www.comet-initiative.org/assets/downloads/COMET%20Webinar.mp4
- COMET PoPPIE Resources: http://www.comet-initiative.org/ppi/researchers

Further resources continued

Tools for reporting and evaluating PPI

- PiiAF (Public Involvement Impact Assessment Framework). http://piiaf.org.uk/
- GRIPP2 (Guidance for Reporting Involvement of Patients and the Public). http://www.equator-network.org/reporting-guidelines/gripp2-reporting-checklists-tools-to-improve-reporting-of-patient-and-public-involvement-in-research/.

PPI reviewing tools

Developed by the course team to help you review research documents.

- Checklist for reviewing research documents
- Plain English summary checklist
- PPI activity planner