



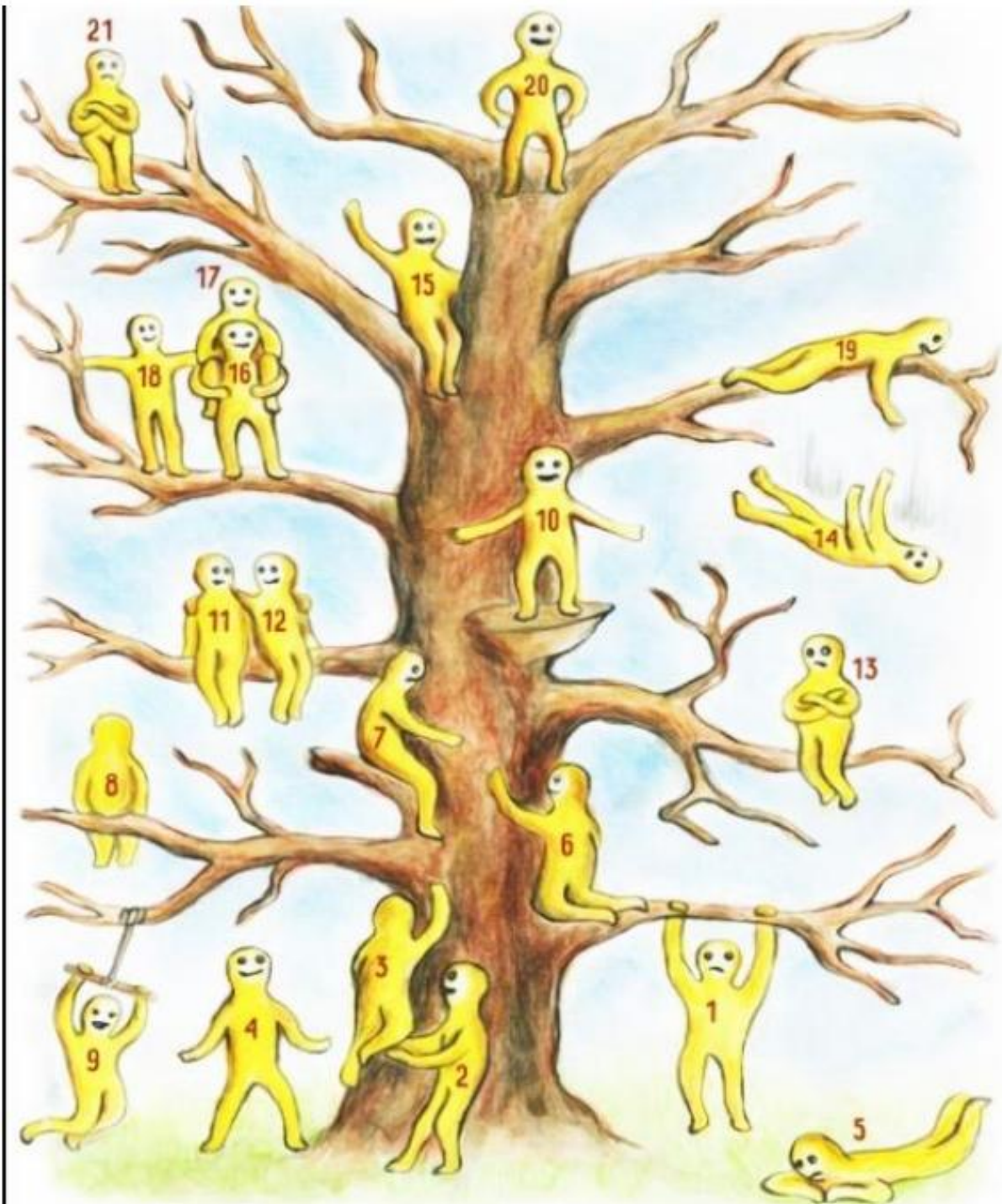
PPI IGNITE
NETWORK

Introduction to Public and Patient Involvement (PPI) Workshop

October 2026



**When it comes to
PPI, who do you
most identify with?**



Workshop Outline

Part 1 Introduction to Public and Patient Involvement (PPI) in Health and Social Care Research	Part 2 Practical Example of PPI (IDEAs Study)	Part 3 Planning your PPI Strategy using the 5 W's of involvement
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What is Patient and Public Involvement (PPI)?

- Doing research '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them (1)
- Members of the public *partnering* with researchers to help decide *what* research is done and *how* it is done (1)
- It is not about...
 - involving members of the public as research participants/subjects.
 - keeping the public informed about your research.

Public Engagement vs Public Involvement

Engaged Research



Public Engagement (PE)

- raising awareness of research



One- way communication

Researchers → Public

Public and Patient Involvement (PPI)

- actively involving people in making decisions about what research is done and how it is done.



Two-way communication

Researchers ↔ Public

What is the rationale for PPI?

➤ Moral and ethical argument

- The people who are most affected by research should have a say in what research is done and how it is done (2)
- Citizens have a right to influence research that is being funded by public money (3)

➤ Pragmatic argument

- PPI can increase relevance, acceptability and accessibility of research (4,5,6)



Why do we need to do PPI?

PPI is increasingly required by:

➤ Research funders

Public and Patient and Carer Involvement (PPI) in the research project	
Are you including PPI in your application? (Yes, No)	Yes
<p>Please describe all PPI at each stage of the research cycle:</p> <ul style="list-style-type: none">• Identifying and prioritising the research question• Design• Conduct• Analysis• Oversight• Dissemination <p>For each stage please include the purpose of this involvement and where applicable how PPI has influenced/changed what work has been planned. The word limit is 600 words.</p>	

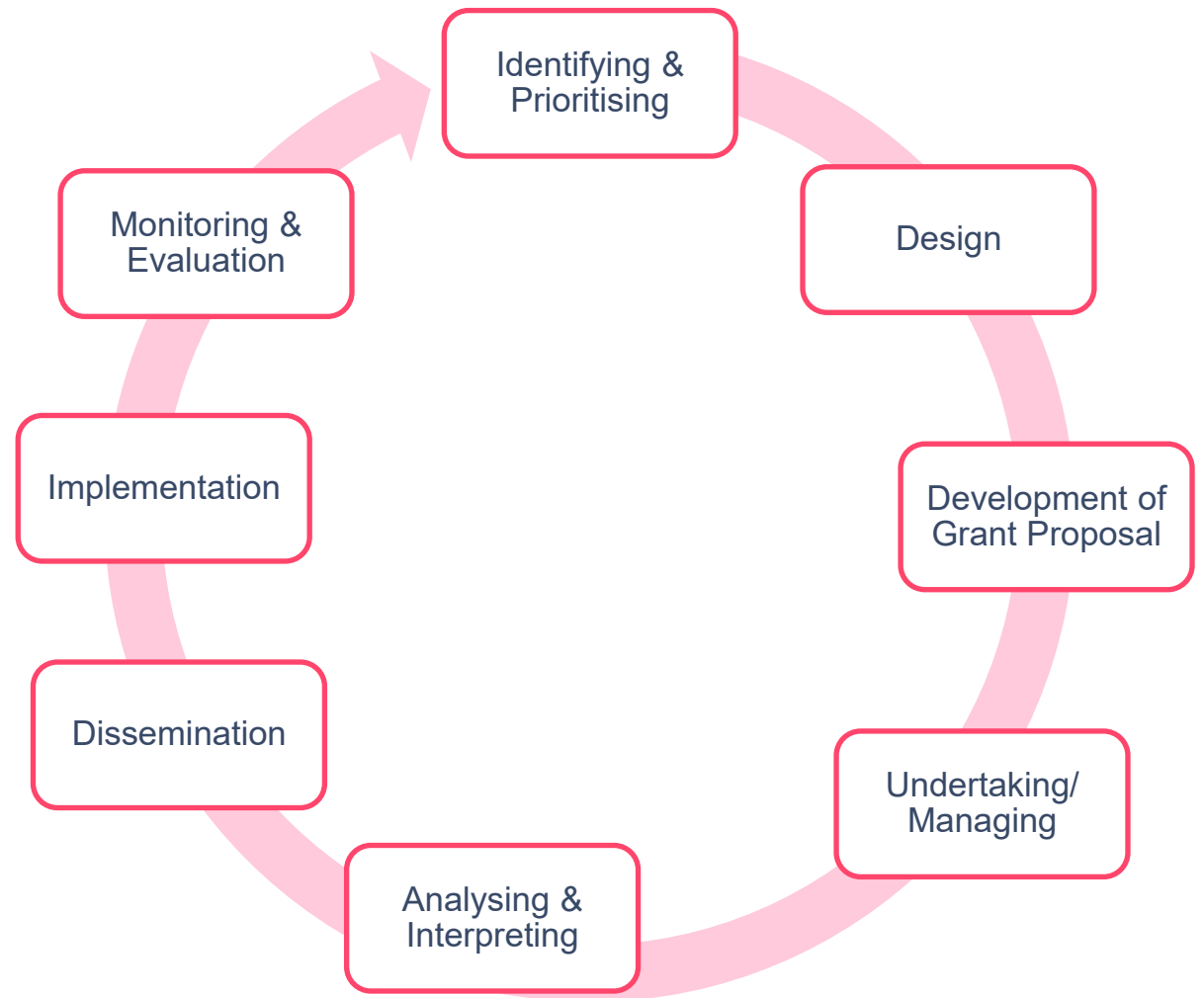
➤ Ethics committees

➤ Academic journals (e.g. BMJ journal portfolio)

When should PPI be conducted?

Stages of Research Process

**The earlier the better but
it's never too late!**



Involvement Approaches

Consultation

When you ask patients and members of the public for their views and you use their view to inform your decision making

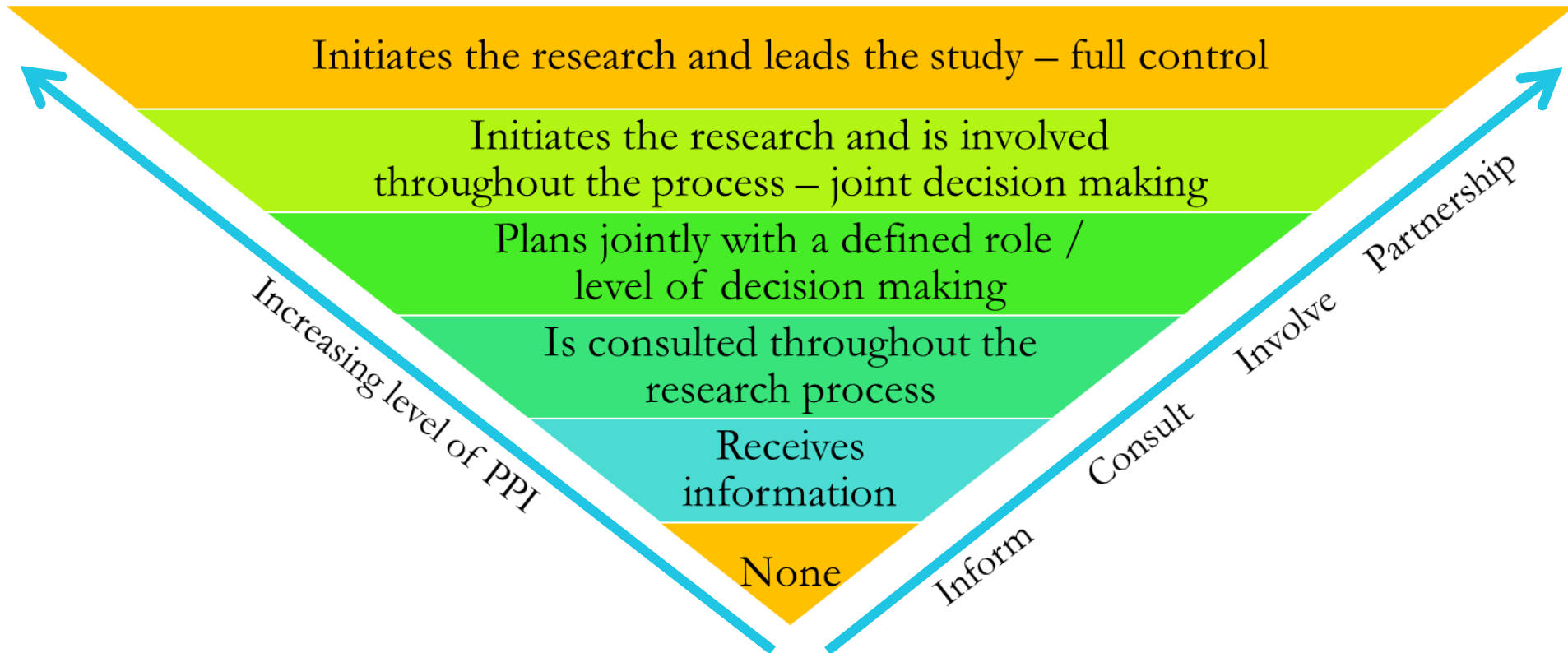
Collaboration

Ongoing partnership between you and the members of the public you are working with, where decisions about the research are shared

User controlled

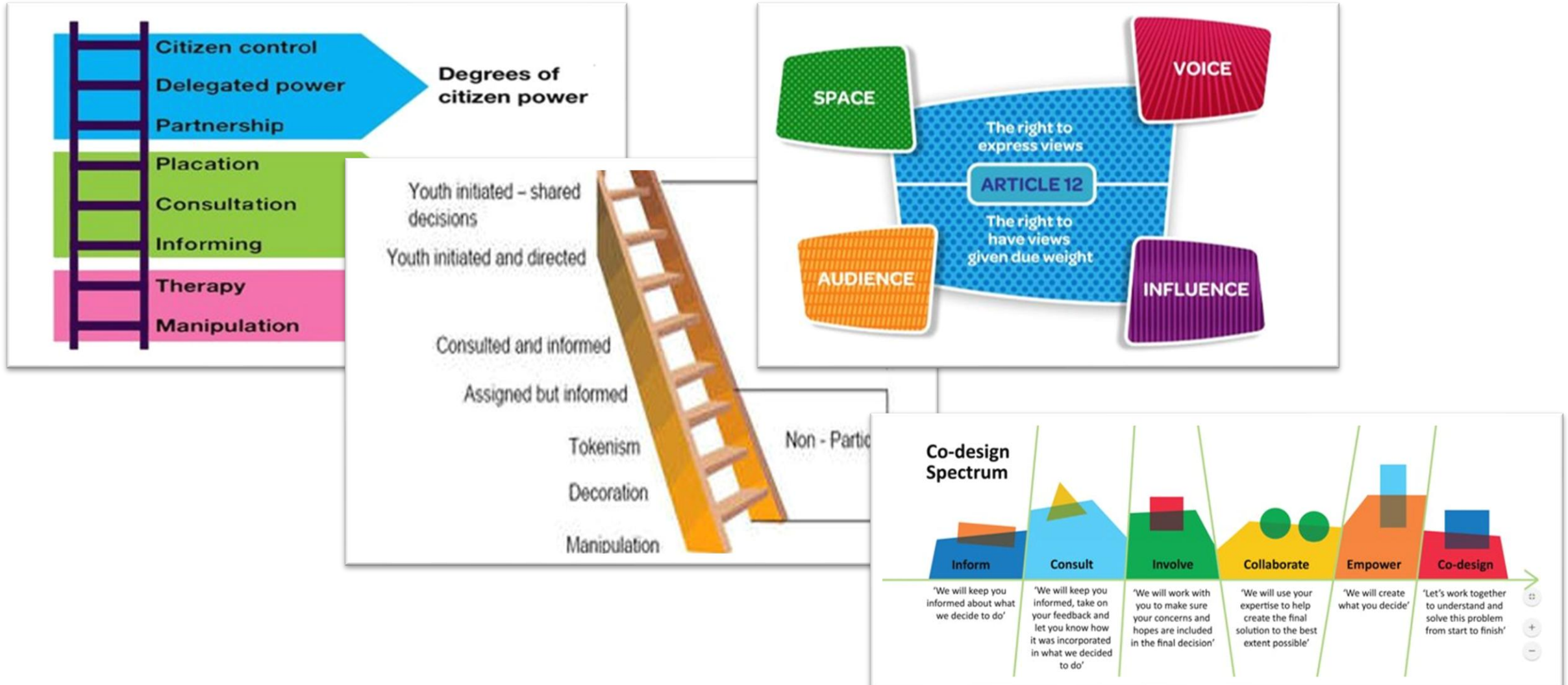
When the research is actively controlled, directed, and managed by service users and/or their service user organisation

Irish Health Research Forum (2013)



(11)

Conceptual models of Involvement



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Designated PPI coordinator

How PPI contributors (members of the public) were identified...

- Various strategies used (social media, diabetes support groups and education sessions, partnered with Diabetes Ireland clinics, GP waiting rooms)
- Panel established (35+ people with diabetes, family members, carers)
- 5 from this panel were recruited to be part of the PPI group.

PPI contributors

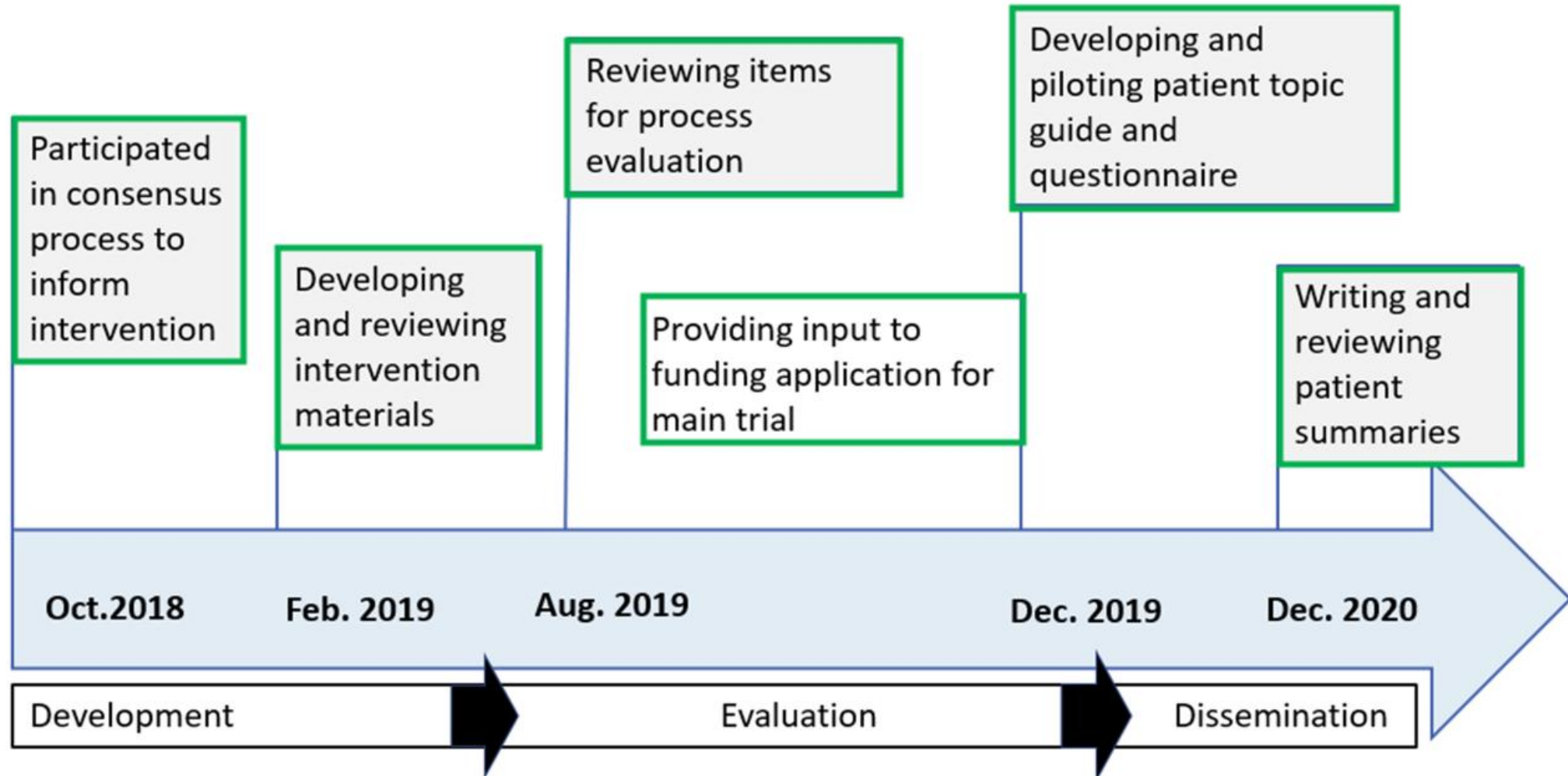
- Good mix of gender, type 1 and type 2 diabetes and urban /rural contributors.

Meetings

- 4 times per year (2 year project).
- Evening time-from 6-8pm.
- WGB (always the same room) and zoom (since March 2020!).
- Refreshments provided.
- Flexible format, powerpoint slides with:
 - Where the project is at
 - How their suggestions from the last meeting were incorporated
 - 2-3 items to discuss and decide on



IDEAs PPI Activities



What difference did PPI make?

Intervention rating long version 24.08.18

Your feedback

Below we describe an intervention to improve attendance at diabetes eye screening. Each possible part of the intervention is presented as a statement. We want your feedback to decide what our intervention should include and how we should deliver it.

For each statement think about whether it is an acceptable and feasible way to improve attendance. By acceptable we mean it is **agreeable**, you like it, and you think it **makes sense**. By feasible we mean you think it **is** can be done.

Please tick which best captures your feelings about each statement. 1 = Completely disagree; 2 = Disagree; 3 = Neither disagree or agree; 4 = Agree; 5 = Completely agree. Please add any additional feedback in the comment box.

Statement	This is acceptable	This is feasible	Comments
GP or practice nurse (name) phone call, text, or letter encourages person to attend screening.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter indicates they approve of screening and hope the person will attend.	1 2 3 4 5	1 2 3 4 5	
Direct the person with diabetes to ask for help, from GP or practice nurse or friends or family, if they cannot complete the consent process themselves.	1 2 3 4 5	1 2 3 4 5	
Person receives a reminder from their GP or practice nurse, to consent and attend their screening appointment.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter gives person the message about how attending screening is taking charge of their health.	1 2 3 4 5	1 2 3 4 5	
Give person a testimonial from someone with diabetes (similar age and profile) for who attending screening was a way for them to take charge of their health.	1 2 3 4 5	1 2 3 4 5	

Intervention rating long version 24.08.18

GP or practice nurse (name) phone call, text, or letter persuades person they will be able to attend their screening appointment, for example by helping them to think about the last time they attended screening, or another appointment.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter addresses the confusion between routine eye checks and screening by clarifying what both tests can and cannot tell them, and that routine checks are not a substitute for screening.	1 2 3 4 5	1 2 3 4 5	
Representative from screening programme (name) call, text, or letter informs person why the programme wants them to attend, that maintaining their vision is their priority, not making money, & a free service.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter informs person why the programme wants them to attend, that maintaining their vision is the priority, not making money, it's a free service.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter encourages patients to see screening as part of whole package of good management, not an extra optional test.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter informs person after appointment they will be reassured all is ok or they can receive treatment if time to stop things getting worse.	1 2 3 4 5	1 2 3 4 5	
Give person a testimonial from other people with diabetes who suffer from retinopathy and emphasises the benefits of	1 2 3 4 5	1 2 3 4 5	

Intervention rating long version 24.08.18

attending, such as being reassured all is ok or being treated early to stop things getting worse

Use message to trigger the person to think about the degree of regret they will feel if they do not go.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter, informs person it is important to go before too late, they personally are at risk and that screening applies to them.	1 2 3 4 5	1 2 3 4 5	
Give person a testimonial from other people with diabetes who suffer from retinopathy and emphasises the benefits of attending screening.	1 2 3 4 5	1 2 3 4 5	
GP or practice nurse (name) phone call, text, or letter emphasises there is no harm from drops used during screening, these are only temporary. Emphasise the benefits overall: temporary discomfort, but overall benefits outweigh this.	1 2 3 4 5	1 2 3 4 5	
Give person a testimonial from other people with diabetes who emphasises there is no harm from drops used during screening and overall benefits outweigh the discomfort.	1 2 3 4 5	1 2 3 4 5	
Encourage person to see screening as a way to achieve a goal (good health, staying healthy, better quality of life) by giving them a testimonial from people with diabetes who attended screening to ensure they have their eyes healthy.	1 2 3 4 5	1 2 3 4 5	

Intervention targeting professionals or the system

Statement	This is acceptable	This is feasible	Comments
Add a new resource to the practice, for example, member of research team, to check patient status (registered, consented, attended) and prepare a patient list of names.	1 2 3 4 5	1 2 3 4 5	
Prompt GPs or practice nurses or both to register patients.	1 2 3 4 5	1 2 3 4 5	
Give GPs or practice nurses or both information about the benefits of making sure their patients are registered and attend, such as results will be available to practice, and their patients will have easier access to screening.	1 2 3 4 5	1 2 3 4 5	
Inform GPs or practice nurses or both of the consequences for patients if they do not attend regular screening, such as eye damage.	1 2 3 4 5	1 2 3 4 5	
Use a patient testimonial to inform GPs or practice nurses or both of the benefits to patients if they are registered and attend, or the risks if they are not registered and do not attend.	1 2 3 4 5	1 2 3 4 5	
Use a patient testimonial to inform GPs or practice nurses or both that patients are more likely to attend screening if healthcare professionals prompt or encourages them.	1 2 3 4 5	1 2 3 4 5	
Give GPs or practice nurses or both feedback on the number of their patients who have not been registered, consented and attended screening.	1 2 3 4 5	1 2 3 4 5	
Give feedback through a source that GPs and practice nurses trust, for example, another colleague or a member of the research team.	1 2 3 4 5	1 2 3 4 5	
Provide feedback with a comparator, for example the % patient attendance at another practice, or national or international figures on screening uptake.	1 2 3 4 5	1 2 3 4 5	
Highlight differences between uptake at the practice and target uptake.	1 2 3 4 5	1 2 3 4 5	

Intervention rating long version 24.08.18

Highlight differences using a source that GPs and practice nurses trust, for example, another GP or practice nurse, a member of the research team, or by international guidelines.

1 2 3 4 5	1 2 3 4 5	
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What difference did PPI make?

Yellow Questionnaire

Here is a list of things that have previously been successful in improving diabetes eye-screening attendance. We would like to get your opinion on whether these things are acceptable and feasible in Ireland.

For each statement, please tick one number in the acceptable category and one in the feasible category.

Each number represents the following:

- 1 = Completely disagree
- 2 = Disagree
- 3 = Neither disagree or agree
- 4 = Agree
- 5 = Completely agree

For example:

Statement	This is acceptable (you like it, and you think it makes sense)	This is feasible (you think it can be done)
Prompt practices to register patients	1 2 3 4 5	1 2 3 4 5

1. Ways that practice can encourage the person to attend

Statement	This is acceptable (you like it, and you think it makes sense)	This is feasible (you think it can be done)
Practice...		
-indicates to person that they approve of screening and hope the person will attend.	1 2 3 4 5	1 2 3 4 5
-sends reminder to person to consent and attend their screening appointment.	1 2 3 4 5	1 2 3 4 5
-gives person the message about how attending screening is taking charge of their health	1 2 3 4 5	1 2 3 4 5
-persuades person they will be able to attend their screening appointment (e.g. for example by helping them to think about the last time they attended screening, or another appointment)	1 2 3 4 5	1 2 3 4 5
-addresses the confusion between routine eye checks and screening test by clarifying what both tests can and cannot tell them, and that routine checks are not a substitute for screening.	1 2 3 4 5	1 2 3 4 5
-emphasises that there is no harm from drops used during screening, these are only temporary. (e.g. overall benefits vs temporary discomfort)	1 2 3 4 5	1 2 3 4 5

1

Statement	This is acceptable (you like it, and you think it makes sense)	This is feasible (you think it can be done)
-directs person with diabetes to ask for help if they cannot complete the consent process themselves	1 2 3 4 5	1 2 3 4 5
-use message to trigger person to think about the degree of regret they will feel if they do not go	1 2 3 4 5	1 2 3 4 5
Practice informs person about...		
-how attending screening is taking charge of their health	1 2 3 4 5	1 2 3 4 5
-why the programme wants them to attend (e.g. that maintaining their vision is the priority, not making money, it's a free service)	1 2 3 4 5	1 2 3 4 5
-after the appointment they will be reassured all is ok or they can receive treatment in time to stop things getting worse.	1 2 3 4 5	1 2 3 4 5
-how it is important to go before too late, they personally are at risk and that screening applies to them.	1 2 3 4 5	1 2 3 4 5
Practice encourages person to...		
-attend screening	1 2 3 4 5	1 2 3 4 5
-see screening not as an optional test but as part of a whole package of minding their diabetes	1 2 3 4 5	1 2 3 4 5
Practice gives person a personal story from someone with diabetes who...		
-is a similar age and profile to them and for who attending screening was a way for them to take charge of their health	1 2 3 4 5	1 2 3 4 5
-suffer from retinopathy and emphasises the benefits of attending (e.g. being reassured all is ok or being treated early to stop things getting worse)	1 2 3 4 5	1 2 3 4 5
-suffer from retinopathy which informs them it is important to go before too late, they personally are at risk and that screening applies to them.	1 2 3 4 5	1 2 3 4 5
-emphasises there is no harm from drops used during screening and overall benefits outweigh the short-term negatives	1 2 3 4 5	1 2 3 4 5
Representative from screening programme...		
-informs person why the programme wants them to attend (e.g. that maintaining their vision is their priority, it's a free service so they are not making money)	1 2 3 4 5	1 2 3 4 5

2

2. Ways that encourage practice to make sure person attends

Statement	This is acceptable (you like it, and you think it makes sense)	This is feasible (you think it can be done)
Add a new resource to the practice, (e.g. member of the research team to check if patients have registered, consented and/or attended)		
Prompt practices to register patients	1 2 3 4 5	1 2 3 4 5
Inform practices about...		
-the benefits to the practice when their patients attend (e.g. practice will not receive the results, their patients will have access to local screening)	1 2 3 4 5	1 2 3 4 5
-the consequences when their patients do not attend (e.g. eye damage)	1 2 3 4 5	1 2 3 4 5
Use a personal story from a patient to inform practices...		
-of the benefits and risks to patients of attending/not attending	1 2 3 4 5	1 2 3 4 5
-that patients are more likely to attend screening if a healthcare professional prompts or encourages them	1 2 3 4 5	1 2 3 4 5
Give practices feedback...		
-on the number of their patients who have not registered, consented and attended screening	1 2 3 4 5	1 2 3 4 5
-through a source that GPs and practice nurses trust (e.g. another colleague or member of the research team.)	1 2 3 4 5	1 2 3 4 5
-on the differences between % attending from their practice and other practices, national and international figures	1 2 3 4 5	1 2 3 4 5
-on the differences outlined above using a source that practices trust (e.g. another GP, practice nurse, member of the research team, international guidelines)	1 2 3 4 5	1 2 3 4 5

Please write comments here:

3

Screening could save
your sight

A message from your
GP about Diabetic
Retinopathy Eye
Screening



**Screening Could
Save Your Sight**

A message from your
GP about
diabetes eye screening

Why we think you should attend Diabetic Retinopathy Eye Screening

- Diabetes can cause damage to the blood vessels at the back of your eye which can affect your sight. This complication of diabetes is called retinopathy.
- It is very important that you have your retinopathy screening. **Everyone with diabetes is at risk** of developing retinopathy. Diabetes can be harming your eyes long before you have any symptoms.
- **Retinopathy screening may be different to the eye checks you might have with your optician.** A good way to know if you have had your eyes checked for diabetes damage is that drops were added to your eyes to temporarily make your pupils larger and photographs taken of the back of the eyes.
- Untreated diabetic retinopathy is the most common cause of sight loss in people with diabetes of working age and it is treatable if detected early. **Early detection of changes to your eyes reduces your**

risk of sight loss significantly as it can be treated more effectively.

- **Some people can be worried about attending screening or finding out something is wrong.** Most people who attend their retinopathy screening are assured that their eyes are fine, but even if there is a problem, treating it sooner prevents it from getting worse
- We appreciate that you have a very busy life and must attend a lot of medical appointments, but **Diabetic Retinopathy Screening is a key part of your diabetes care.**
- **At your screening appointment** you will be called into a consultation room to have drops put into your eyes. You might find this uncomfortable and your vision somewhat blurred, but their effect is temporary and they are not harmful. It only takes about an hour for the appointment.

Remember the Diabetic RetinaScreen service is free.

Turn over the page to find out what to do next to attend screening



Why we think you should attend diabetes eye screening

Diabetes eye screening is provided by RetinaScreen, the free national diabetes retinopathy screening programme.

Here are 5 reasons why we think you should participate:

1

Diabetes can cause damage to the blood vessels at the back of your eye which affects your sight.

This complication of diabetes is called retinopathy.

2

Everyone with diabetes is at risk of developing retinopathy.

Diabetes can harm your eyes long before you have symptoms so it is very important that you attend screening. Diabetes eye screening is an essential part of your regular diabetes care.

3

Routine eye checks you might have with your optician are different to the national screening service.

Even if you attend an optician regularly you should still attend screening with the national RetinaScreen service.

4

We understand you might be worried about attending screening or finding out something is wrong, **but most people who attend screening are reassured that their eyes are fine.**

5

Attending screening dramatically increases the chance of damage being picked up early and treated in time.

Untreated diabetic retinopathy is a common cause of sight loss in people with diabetes, but it is treatable if picked up early.

Remember RetinaScreen is free



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NETWORK

A high-angle photograph of a person walking away from the camera on a dirt path in a park. The person is wearing a dark jacket and carrying a red bag. The path is bordered by green grass and a paved walkway. A tree and a bench are visible in the background.

User Experience

Design

Workshop Outline

Part 1 Introduction to Public and Patient Involvement (PPI) in Health and Social Care Research	Part 2 Practical Example of PPI (IDEAs Study)	Part 3 Planning your PPI Strategy using the 5 W's of involvement
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Planning your PPI



Important to remember!



5W's of Involvement

Why?

Why are you involving people?
What do you think they will add/ help with?

Where?

Where are you going to find people?
Where are you going to advertise?
Where are you going run meetings?

What?

What will they do in your study?

Who?

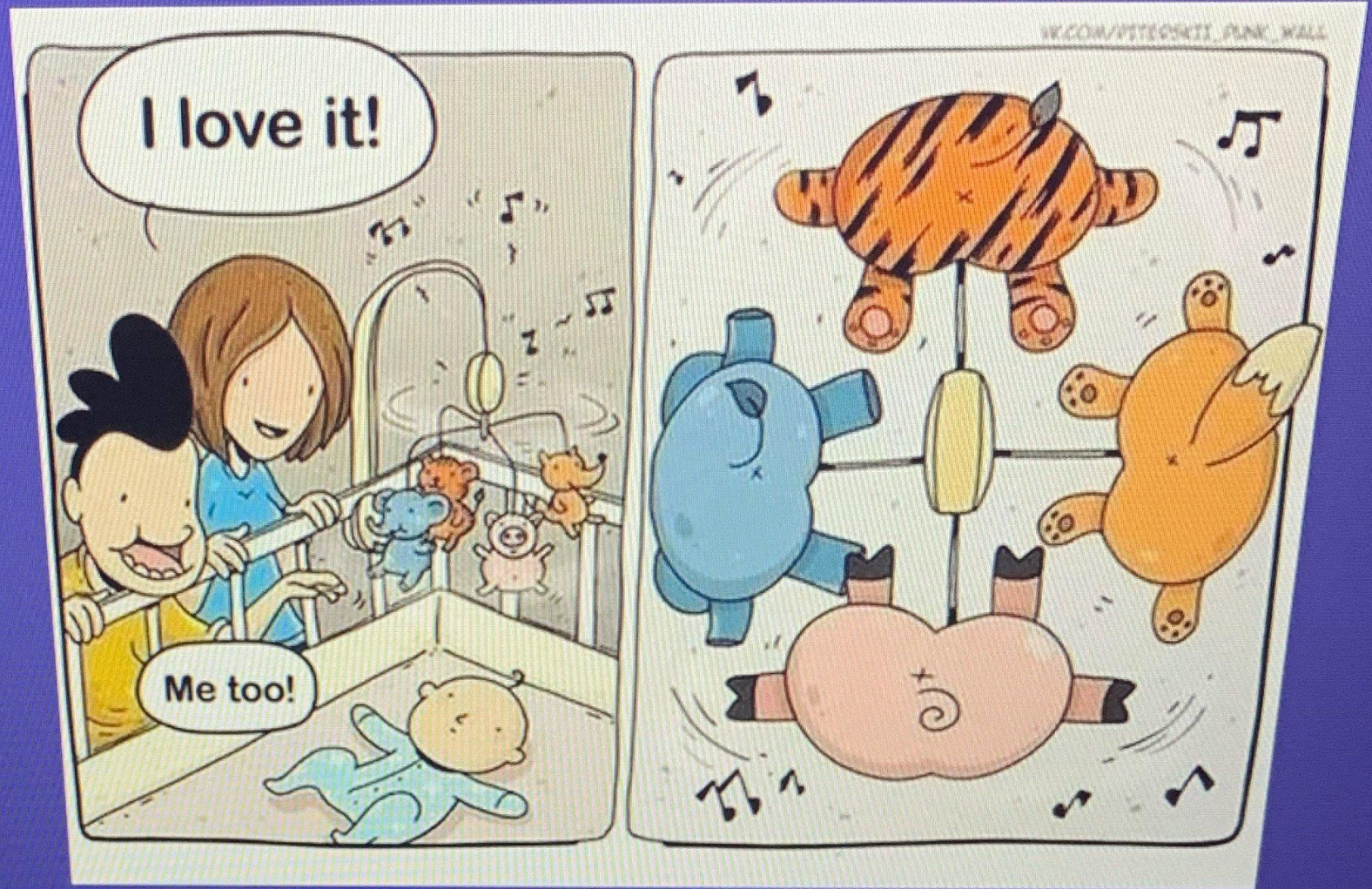
Who are you involving?
Who is facilitating/ co-ordinating (power dynamics)

When?

At what stages?
(this links back to your why?)



The importance of the user perspective



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