

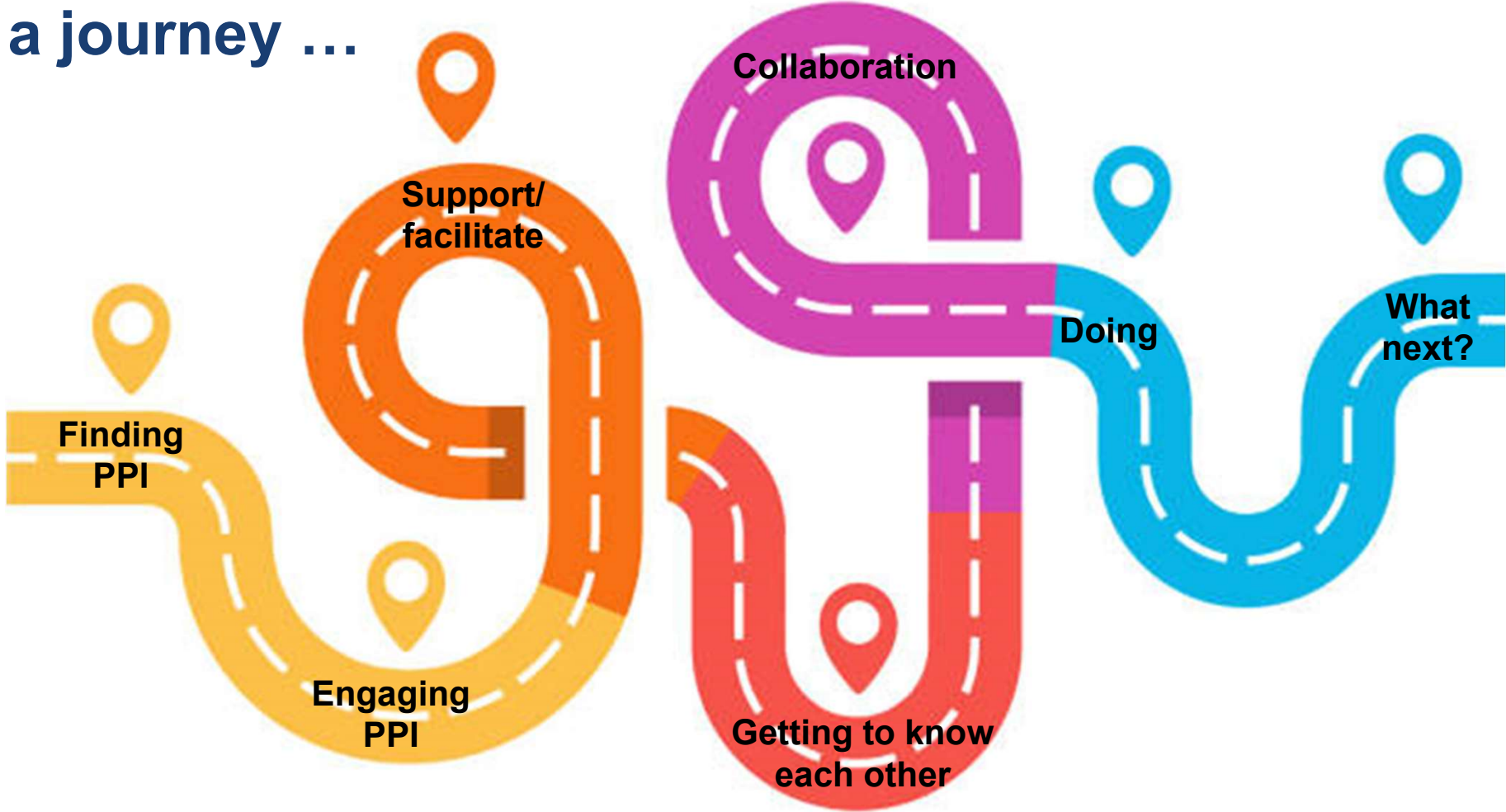
Challenges and desired outcomes: Co-designing a trial exploring the impact of chronic pain after cardiac bypass surgery.



Researcher Karen Ainsworth
NIHR ARC NENC Practice Fellow
(Lead research nurse at The James Cook University Hospital)



It's a journey ...



Lots of challenges and desired outcomes.

10 minutes

Focus on PPI

Tale of 2 halves!



Was PPI essential?

Commitment Encouraged **It's a given** **New skills/experience**

Passing 'phase' or 'buzzword'? **Network**

'UK Standards for Public Involvement'

Including all perspectives and skills **Exciting**

Project justice Avoid 'lip service' trap **Legal responsibility**

Prove my worth 'Co-production'

Give patients a voice

Representative

Finding PPI...



Take my own advice...

“Don't let fear paralyse”

“Bite the bullet”

“Take the plunge”

“Fake it till you make it”

“Reach out”

“Network, network, network!”

Who were the PPI?



Representative?

Retention!

Respect –

wishes

anonymity

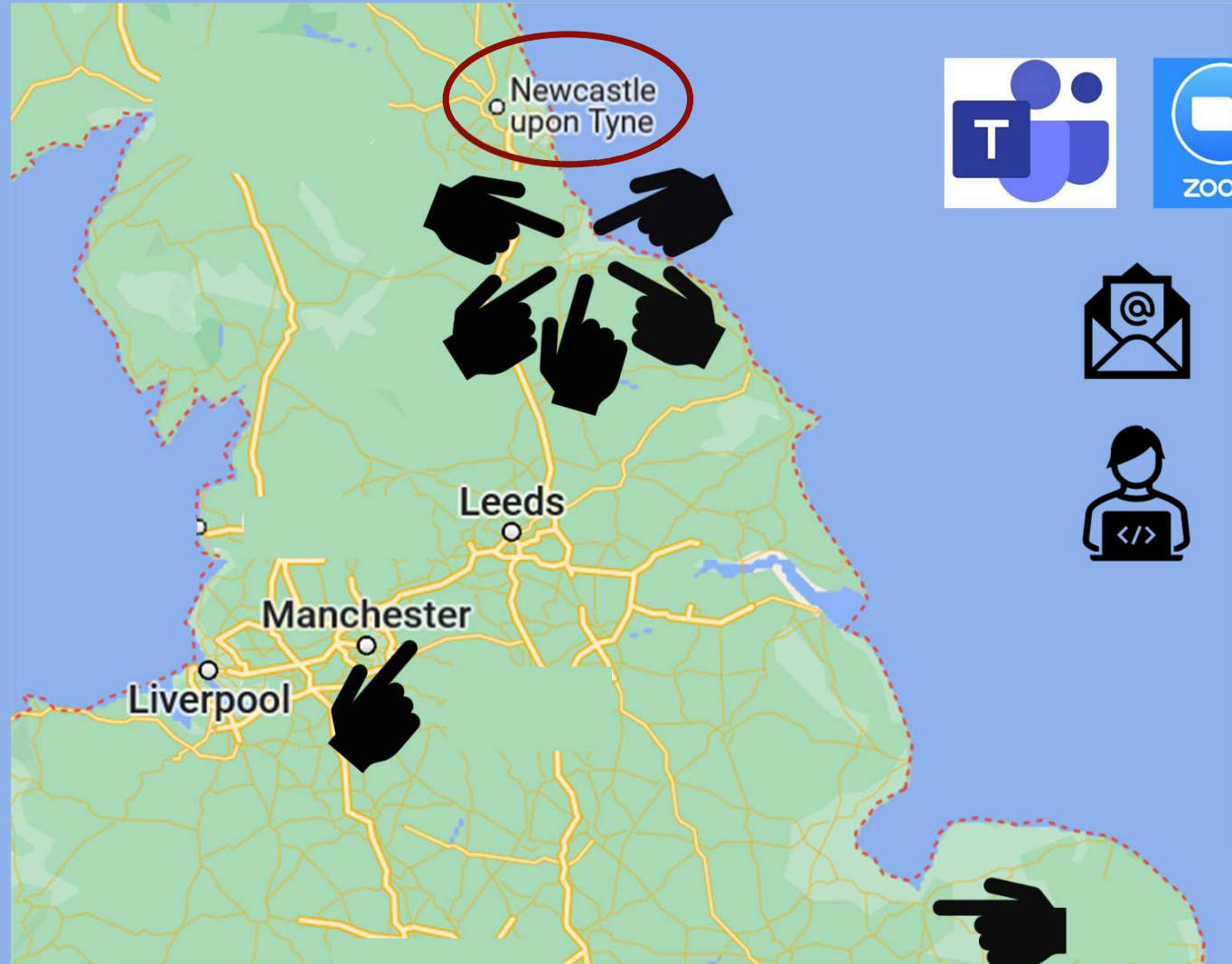
contributions

communication needs

Geography!

££££

Location,
Location,
Location...



PPI



Meeting Karen on-line

@ a CSG PPI when she talked re project.

I was invited

to help in this project by the BHF and am happy to do so.

If some effort may **bring answers** and hence **solutions**, I was willing to volunteer.

I must have said some right things

for her [Karen] to think that I could help.

Pain, lots of it,

after 3 years post-surgery, you look for relief by any means. Currently looking at acupuncture and others.

What drew you to this project?

I've experienced **no barriers** to contributing as I'm very experienced in this arena. Online meetings and reviewing by email works perfectly.

For me **none.**

All good. Listened to and considered my point of view.

Other than finding a practical method to get to **"The Helix"** I have not been inconvenienced or found any barriers to anything.

Being able to ask fundamental questions that could not be asked in clinic because of time constraints and getting answers.

It was not just me in trouble.

There may be benefits at some point for face to face meetings, but living in Norfolk **the cost** of contributing is impossible.

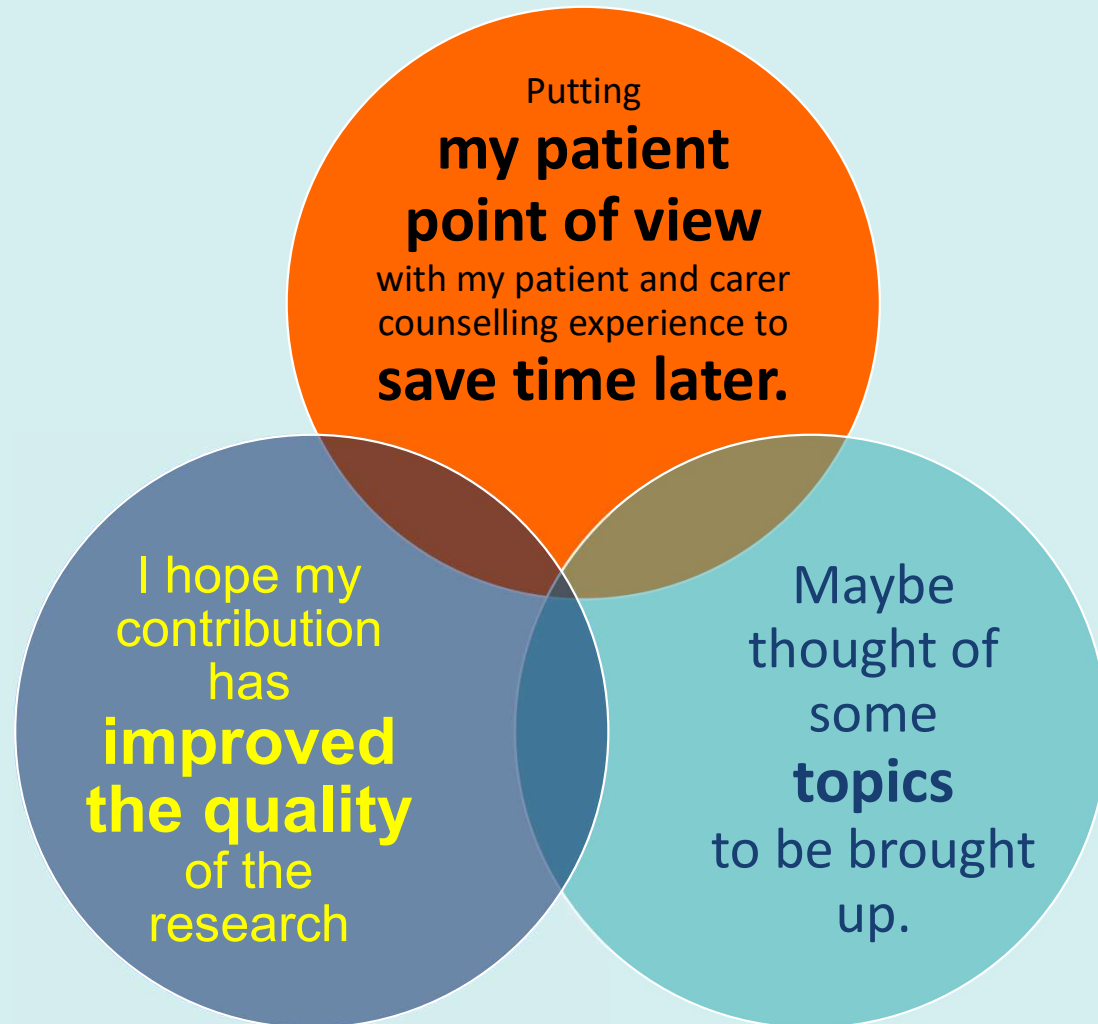
Meeting people that understood pain.

(bad) Maybe reading 84 pgs. came close!

What is good/bad about your experience to date?

What are the barriers to you contributing to this project?

*How do you hope
your input has/will
help?*



What are the barriers to implementing this project and changes after analysis of results?

Jargon & acronyms
(LOL!!)

RECRUITMENT

[of suitable candidates]
- the weakest link

PAIN

Qualification, descriptors.
One person's agony is another's ache.

INTERPRETATION

£

One could claim less pain would be a saving in prescriptions and consultations.

Inertia to change

Time

E.g. "My partner got depressed because of my constant griping about the pain"

Potential for PPI to be involved in analysis, but the logistics of that can be challenging.

What would you hope/anticipate could be implemented in practice following analysis of results?



Less post operative pain experiences.

Improved patient experience & information to help them in that process.

There will be reflection by clinicians both in primary and secondary care that whenever they have a patient in front of them presenting with the need for cardiac surgery, an opportunity is made to discuss the topic of post surgical pain.

The more the patient is prepared for surgery the better their experience will be, the less anxious they could be when that happens.

Sometimes the culture is that 'we won't mention X because we don't want scare the patient', but this is ultimately unhelpful.

Thank you

Please contact me if you have any questions.

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*Office hours 8am to 4pm.
Out of hours an answer phone is available to leave a message.*

