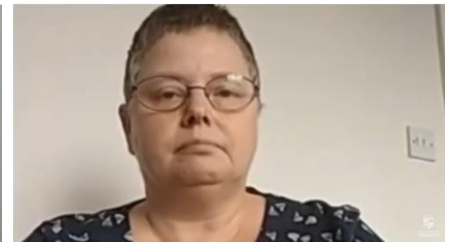


Values and value in patient & public involvement: Moving beyond methods

Rosemary Hollick
Lynn Laidlaw
University of Aberdeen



Vasculitis Outcomes In relation to Care Experiences Study

What is vasculitis?

- Group of rare inflammatory diseases that cause inflammation of the blood vessels
- Involves many different organs e.g., kidneys, heart, lungs, nerves, ears and eyes
- Serious adverse outcomes
- Complex / expensive treatments
- Individual care needs are very different
- Early recognition and diagnosis, followed by appropriate and effective treatment, is important to prevent damage

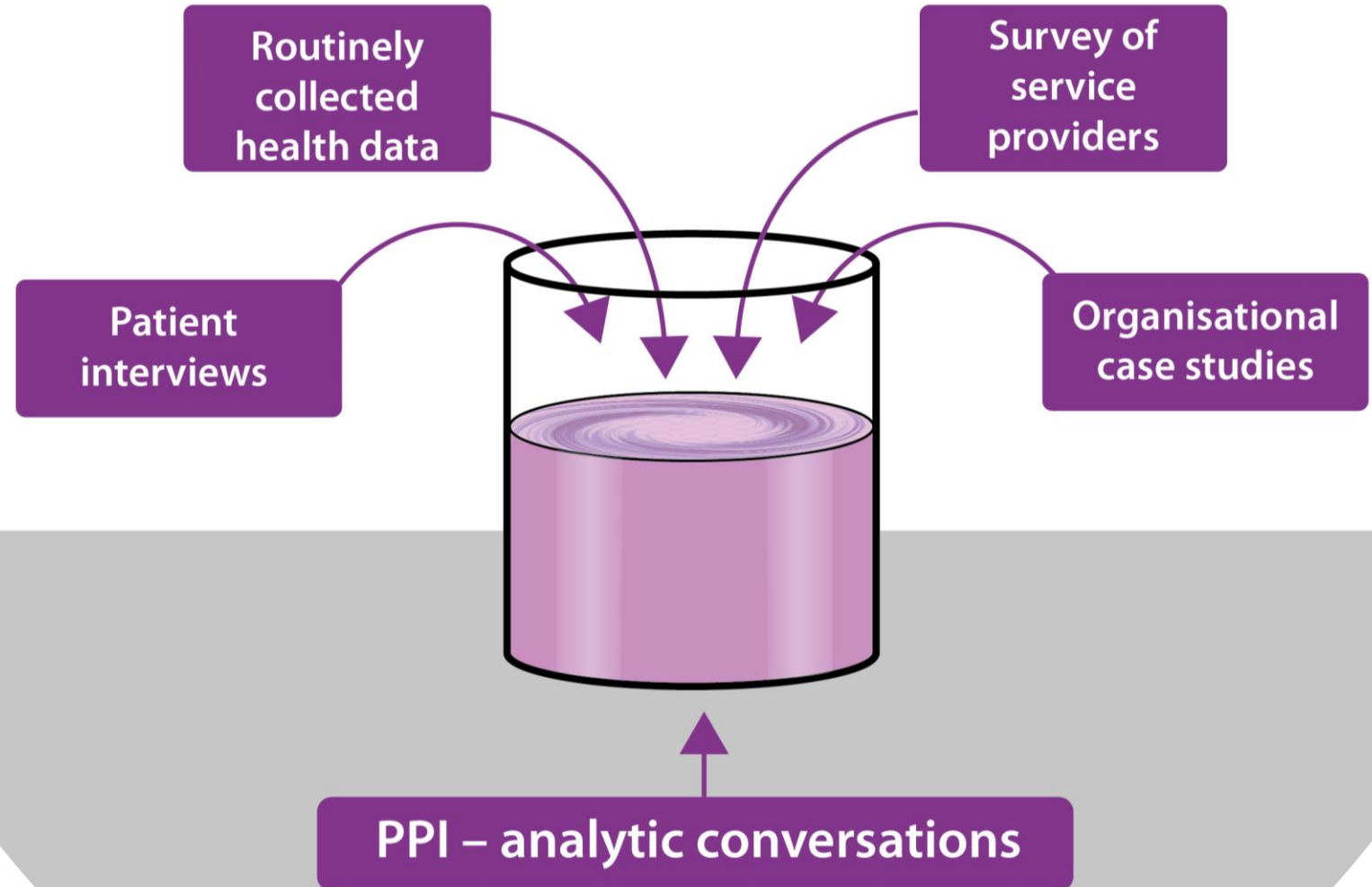
What VOICES set out to do?

Identify **key service components**
underpinning good
care

Explore the link
between service components and
individual health outcomes

Examine **barriers and facilitators** to
implementing
service components
in practice

What we
did...



Systemic Vasculitis

> Overview

- > About vasculitis
 - Thoughts on what systemic vasculitis is
 - Thoughts about causes of systemic vasculitis
- > Vasculitis diagnosis
 - Symptoms of systemic vasculitis
 - Challenges of getting to a systemic vasculitis diagnosis
 - Investigations leading up to a systemic vasculitis diagnosis
 - Being given a systemic vasculitis diagnosis
 - Thoughts on missed opportunities for a systemic vasculitis diagnosis
- > Treating vasculitis
 - Treating systemic vasculitis
 - Managing systemic vasculitis flares and seeking help
 - The damage that systemic vasculitis does to the body
 - Making decisions about increasing redness or changing systemic

Systemic Vasculitis

Overview



In this section, you can find out about the experience of having systemic vasculitis by seeing and hearing people share their personal stories.

“Research is how medicine and healthcare move forward. We, the patients, are the partners of the scientists, medical professionals and other researchers who make it happen. Our role is crucial. Without us, there is no research. Without research, there is no progress.”




Steve

What do we mean by ethic of responsibility?

- Responsibility to attend to different perspectives
- Implicit in trusting relationships is mutual care and respect



More than a method: trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production

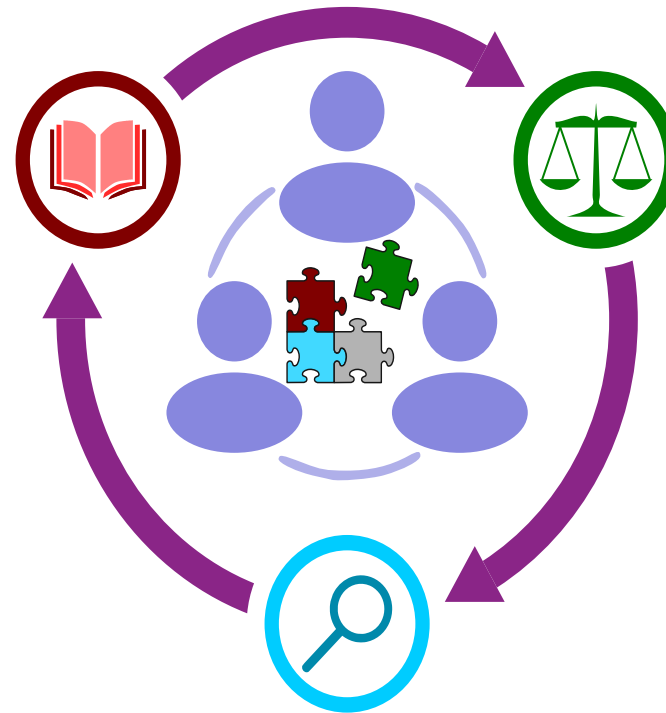
[Sarah E. Knowles](#) , [Dawn Allen](#), [Ailsa Donnelly](#), [Jackie Flynn](#), [Kay Gallacher](#), [Anmarie Lewis](#), [Grace McCorkle](#), [Manoj Mistry](#), [Pat Walkington](#) & [Jess Drinkwater](#)

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Analytic conversations

We are all learning together



Ongoing conversations shape our decisions

Different perspectives are good but can feel uncomfortable

Locock et al. Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement [Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement - PMC \(nih.gov\)](#)

More
than a
method...

Reflexivity
Analytic
conversations
Ethic of responsibility
Relationships
Collaboration
Productive
tensions
Resources
Time



Adapting and changing the recipe over
time
Key elements are baked in, not sprinkled
on top as an afterthought

Thank You

