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- Pelvic mesh implants were widely used to treat stress urinary incontinence and pelvic organ prolapse: **127,532** women were treated with mesh in England between April 2008 and March 2017¹.
- Concerns emerged about serious complications², prompting restrictions in the UK in 2018.
- Estimates suggest 12% of women experience complications³
- Women have described feeling dismissed, dehumanised, and frustrated that their knowledge of their own bodies was discounted^{2,4,5}.
- These experiences occur within the context of considerable uncertainty, not only regarding the causes and management of pain, but also in how healthcare is accessed and navigated.
- **We asked: “How do women and clinicians experience and manage uncertainty during the care of complications associated with pelvic mesh implants, and what does this reveal about the organisation and delivery of care?”**

“What do you find the hardest in your interactions with the medical field?”

“What are the things that you really appreciate?”

“Some people describe feeling uncertain about their health, and what is causing their problems. Can you say something about that?”

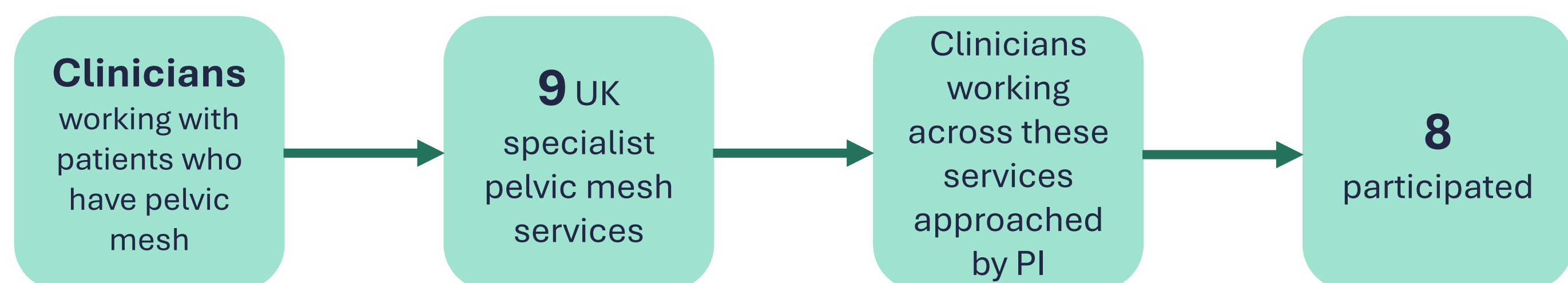
“Some patients mention other complaints that may or may not be related to the mesh implant, such as fatigue. Do you have any thoughts about this? “

“What do patients tell you about their journey in the NHS?”

“What have you found gets positive feedback from patients?”

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graph LR; A[Patients
Women with pelvic mesh complications] --> B[69 invited
via Cambridge specialist mesh service in 2022]; B --> C[20 expressed interest]; C --> D[11 participated]
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- Patients**  
Women with pelvic mesh complications
- 69** invited  
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| Age               | Reason for mesh                                                        | Mesh implant                                                                      | Year of initial surgery |
|-------------------|------------------------------------------------------------------------|-----------------------------------------------------------------------------------|-------------------------|
| 43-69 (M = 54.91) | 8/11 for stress urinary incontinence<br>3/11 for pelvic organ prolapse | 10/11 mid-urethral sling procedures (TVT, TVT-O, TOT)<br>1/11 sacrocolpopexy mesh | 2006 - 2017             |



| Sex              | Specialism                          | 6/9 services represented                                                                                                                                                                   | Specialist since |
|------------------|-------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| 5 male, 3 female | 5 urogynaecologists<br>3 urologists | Sheffield Teaching Hospital<br>Newcastle Hospital NHS Trust<br>North Bristol NHS Trust<br>Greater Glasgow & Clyde NHS<br>Manchester University NHS Trust<br>Cambridge University NHS Trust | 2006 - 2020      |

# Making Sense of an Uncertain Clinical Picture

"I don't know what's related ... I have never been told what is related to what isn't" (P7)

## Making Treatment Decisions Amid Uncertainty

Patients and clinicians weigh uncertain treatment benefits against potential harms.

“When I have this surgery in a few weeks time, what it’s gonna resolve?” (P9)

## Seeking knowledge beyond clinical encounters

“Who do you believe?” (C6)

**When clinical evidence  
and lived experience  
diverge**

Recognition of mesh-related complications in primary care is challenging and inconsistent.

“They tell me that they've had a host of referrals, pathways” (C3)

pathways and fragmented care contribute to delays in accessing specialist services.

### Repeated Investigations and Tests

Fragmented care results in repeated investigations, adding burden for patients and clinicians.

### Emotional Burdens of Fragmented Care

Patients felt they were “floating about” between services, repeatedly recounting their symptoms.

### Impacts on Personal Relationships

Patients described impacts on relationships with partners, children and family roles.

“This has been a really confusing journey, difficult to describe, difficult to understand, humiliating, embarrassing.”  
(D18)

### Impacts on Relationships with Healthcare Professionals

Being passed between clinicians left patients feeling unheard, misunderstood and dismissed.

### Seeking or Avoiding Further Medical Help

Some patients are too emotionally fatigued to continue seeking care.

“But I’m at the stage now, I don’t even want to go to the doctor’s because I really don’t want anymore”. (P3)

## Clinical Practices

## Listening

## Acknowledging

the patient

Honest communication

uncertainty

Establishing realistic expectations

"I thought, this woman is listening to me, and she's believing what I'm saying, she's understanding." (P9)

“I think if people are just more calm and slow, and I'm not just another one on the list, because I'm not a normal person on that list...” (P1)

## Service Structures

Specialist mesh services

Multidisciplinary

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care

## Continuity

"I think it's the multidisciplinary approach for women who, for example, are not going to have any surgery, they find it reassuring, being investigated from all aspects." (C4)

**act** Addenbrooke's  
Charitable Trust

**THE UROLOGY FOUNDATION**

- In care for pelvic mesh complications, patients and clinicians experience clinical uncertainty about the causes of symptoms and treatment options.
- Clinical uncertainty was exacerbated the infrastructure of healthcare delivery.
- Person-centred communication and coordinated specialist services helped women feel heard, navigate care and feel supported in making treatment decisions.
- Pelvic mesh services, and women's health services more broadly, can mitigate uncertainty by adopting the person-centred clinical practices and service structures.