

# Experiences of the early 'infertility journey': An ethnography of couples commencing infertility investigations and treatment

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# Infertility



- Significant life event
- Universal
  - Worldwide estimates 70/80 million
  - One in seven couples in the UK
- Definition

**”Disease** of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (WHO, 2009)

# Infertility treatments



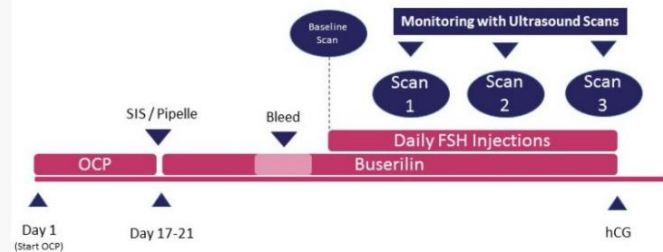
- Advice, surgery, ovulation drugs
- Adoption, fostering
- Assisted Reproductive Technologies : In Vitro Fertilisation (IVF)
  - Increasingly commonplace
  - ~ 2/3% babies born UK

# Metaphor – ‘Infertility Journey’

## The Treatment Journey

[Home](#) » [Treatments](#) » [The Treatment Journey](#)

### A typical Treatment Cycle



## Your Journey Through Fertility Treatments

What are your first steps?

If you're hoping to secure NHS funding for your treatment

You should arrange to see your GP, who may refer you to a local hospital for consultations and possibly treatment. The hospital consultant may decide to refer you to an NHS approved specialist fertility centre, such as Bourn Hall Clinic.

If you choose us, we'll get in touch and guide you through the next steps of your journey. This will include an individual consultation with one of our fertility specialist doctors.



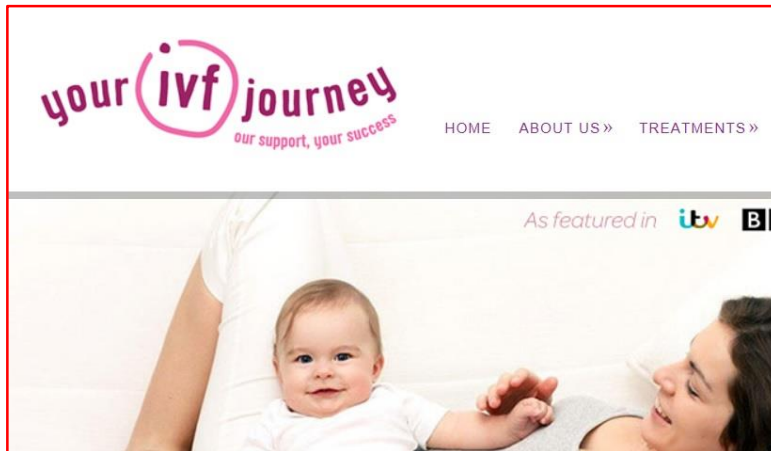
"Every journey is different, every treatment is individual"

## Personal Stories

### My Story: My Emotional Journey Through Infertility

**Sarah Koval**  
Spring 2014

Wake up at 5:00 a.m.  
Rush downtown to be at the clinic just as the doors are opening (any later and my wait time would be multiplied).  
Sign my name on three clipboards and then wait in waiting room #1 for my name to be called.  
A nurse takes my blood.  
Move to waiting room #2 and wait for my name to be called.  
A technician performs my vaginal ultrasound.  
Go back to waiting room #2 and wait for my name to be called.  
The doctor reviews my chart and updates me on my progress.  
Go back to waiting room #2 and wait for my name to be called.  
A nurse reviews my medication and gives me my injection in the butt (she tries to maneuver around the sore black and blue welts from the previous day's injection).  
Rush to work and sneak over to my desk quietly, hoping my colleagues don't notice that I'm late for the third time this week.  
Lather. Rinse. Repeat.



# ‘Paying attention’ to the journey

- Physically, emotionally and financially demanding
- Overall success rates ~30%  
Treatments evolve – ever more technological, distant from care  
Clinic – semi public space, liminality (Allan, 2007)
- Increase negative feelings, depression
- Reason discontinuation of treatment
- Costly ~ £7k cycle, postcode lottery
- Everyday experiences of those encountering infertility and technologies together



# Study aims



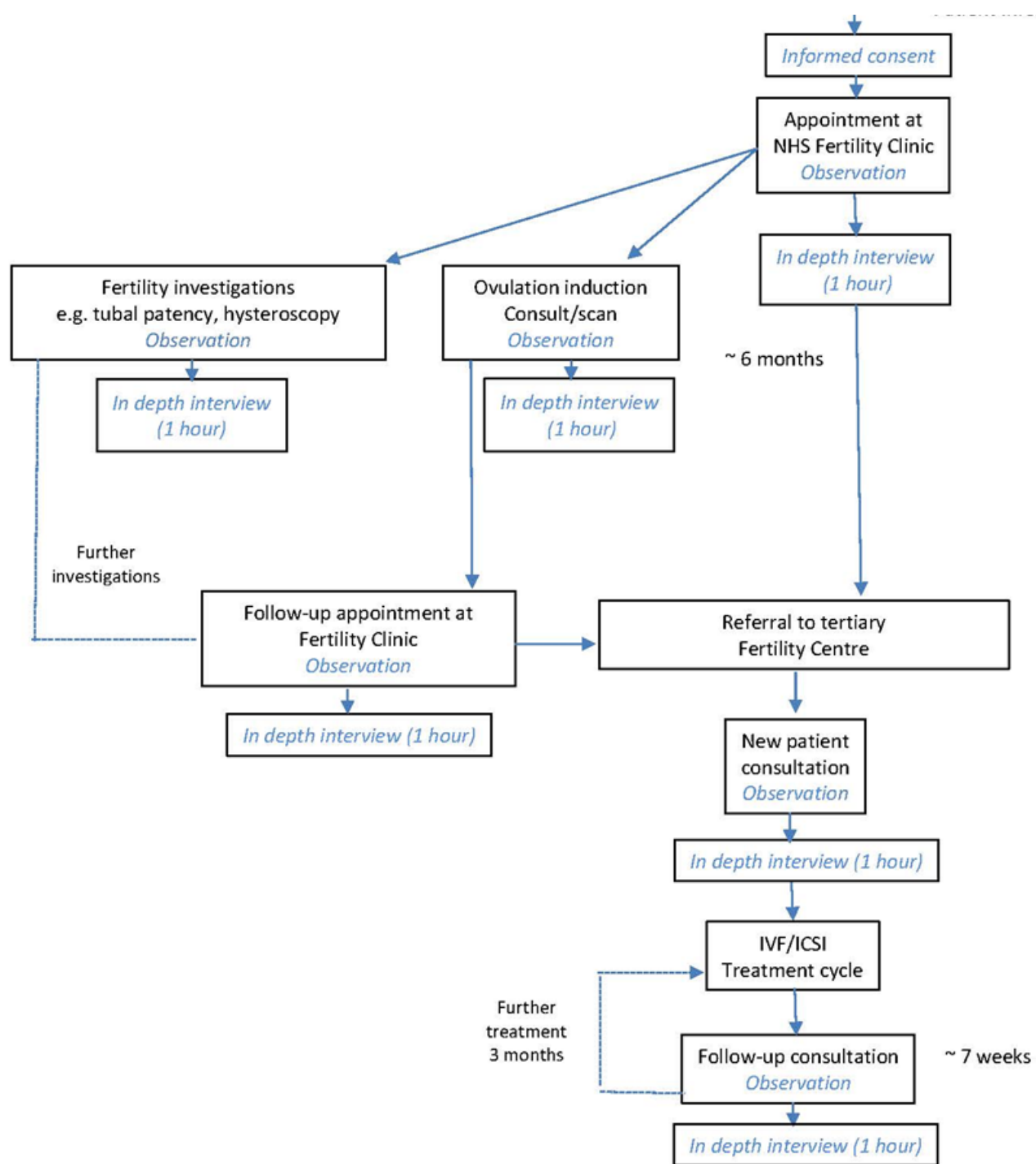
- Aim to **examine the social process** of negotiating fertility treatments through description, interpretation and understanding of its social meaning
- Overall research question  
“what is the lived experience of **couples** starting treatment for infertility?”  
how does this experience change **over time**

REC: 12/SC/0571

# Study design



- Longitudinal ethnographic research study
- Study participants
  - Couples attending a hospital based fertility clinic, initially first appointment and thereafter for any subsequent appointments
  - Concluded participation after completion of treatment cycle (such as IVF) or other exit, for example, becoming pregnant







# Data collection

- Fourteen (14) couples
- Repeated
  - **Interviews**
  - **Participant observation**
  - **Field notes, diary**
- Data collection period (18 months)
- Thematic analysis

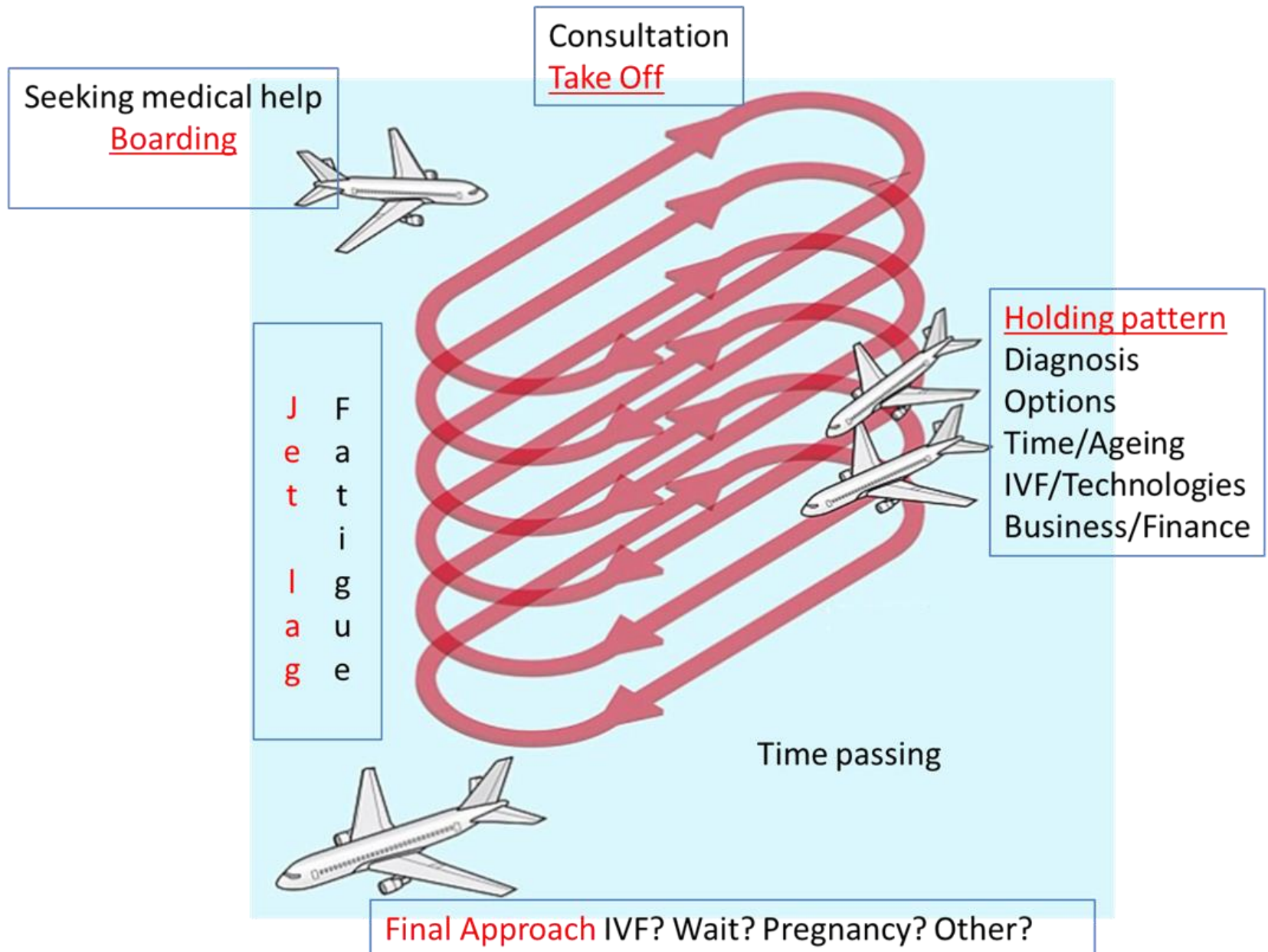


# Analysis - Development of journey metaphor



The junction box offers several possibilities such as a continuation of the journey, signpost to alternative destinations or an opportunity to change route or vehicle. The junction is not always helpfully configured and may in fact sometimes be the cause of unexpected delays.

# Themes of the infertility journey



# Passengers



- **Couple**
- Becoming a patient
- **Sick role** of being 'fertility patient'
- Both **desired** (legitimises) and **stigmatised**
- Narrative of **persistent patient** challenged



🏠 > Science

# Lionel Shriver: parenthood is not a human right and the NHS should not fund fertility treatment

## DR MAX THE MIND DOCTOR: No one has the right to have a child

By MAX FEMBERTON FOR THE DAILY MAIL

PUBLISHED: 01:46, 17 September 2016 | UPDATED: 01:46, 17 September 2016

       18 

# Jet lag

## Fatigue

- **Relentless**

“yeah but there hasn’t really been, in six and a half years, a time when we haven’t been trying, apart from on the recovery times from her two laparoscopies”

“I wonder how many years they went through..of *just year after year after year* before it finally got to the stage where they thought ‘right this is it, it’s not going to happen let’s give up”

- **Repetitive, physical**

“I feel it is kind of it is a real rollercoaster, just because of the nature of the fact you’re going through cycles, I mean you are. It is physically a rollercoaster. So every month I do get very emotional because my hormones are telling me ‘come on’ [laughing], ‘get on with it!’ and that as I’ve got older seems to have got worse as well”

# Taking off

- **Anticipation**

“just a relief to *get there* because it’s such a long process ..I was quite.. eager to *get there*, to see what was going to be said”

- **Uncertain** what / how this would manifest
- Desire for **empathy**, emotional support
- **Explanation** and **diagnosis**

# Taking off Consultation

- **Options (lack of?)**

“..a bit more of a menu..of graded possible options that you could try to help you out”

- **IVF routine, ubiquitous**

“basically try ‘IVF’ or ‘try your luck’ kind of thing”

“..sort of said that’s the next step if you want to do it or you can *cut to the chase* and just do IVF. Which I sort of felt was a bit.. not pushed, but that was just the sort of..you can do that if you want to, if you’ve got the money, sort of thing..”



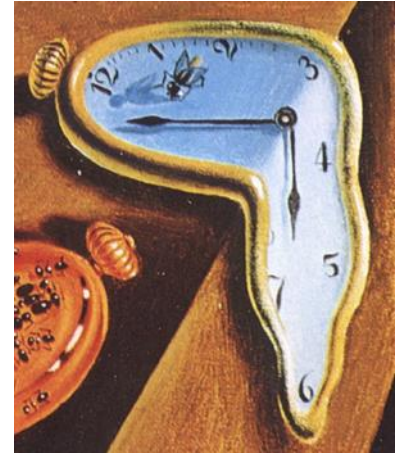
# Holding pattern

‘the flight path maintained by an aircraft awaiting permission to land’  
‘a state or period of no progress or change’

- ‘Mazing’ theory - pursuit of parenthood
- Recursive, repetitive (Sandleowski et al, 1989)
- Revisiting ideas
  - Diagnosis
  - Options
  - Time/ageing
  - IVF/technologies
  - Finance

# Time/Ageing

- Time passing, biological time limited
  - Waiting, lack of control
- Future time
- Past (wasted) time
- Present time (staying in moment)



# IVF/technologies

## Becoming routine

“it feels like it might *help us get to where we want to be* so that’s why I was hoping that’s what they would say”

“People just go, ‘Oh you’re having trouble, just have IVF!’ and not realise what a big deal it is. And how long it can take”

## Technological, mechanical

“all the hormones and the injections and the stress and the y’know..?”

“well I am asking myself, do you really want to have a baby *this way?*”

## Funding

“at the end of the day you’ve still got to have the 6 thousand pounds to spend to do it in the first place. Y’know then it’s the 6 thousand and then if it doesn’t work do you have another go ?”

# Treatment experiences

- Couples – **joint** construction
  - **Female** – physical body, instigate, historical
  - **Male** – supportive, conflation with sexuality, produce ‘sperm’
  - Clinic reinforces
- **Consumers**
  - Role encouraged, self-care model
  - Not fully empowered (recognition, funding)
- IVF Clinics – ‘**semi-public**’/commercial
  - Some suspicion of treatment options

# Landing

- Destinations
- Uncertainty remains
  - Technology - 'never enough'
  - Open-ended quality
- 'Journey without end'

# Conclusions

Couples' experiences (narratives) contrast with promise and hope implied by 'journey' metaphor.

- Experiences are **challenging**, not routine
- Couples are cautious to being patients /starting treatments.
- **Commercialisation** (including payment) of fertility treatments is unexpected for couples.
- **Ubiquity** of ARTs reduced 'choice'.
- **Couples** jointly involved : clinics focus on the female partner.
- Journey is recursive and '**open-ended**' , even with pregnancy.



# Acknowledgments

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