

Examining the communication of diagnostic uncertainty: an empirical ethics approach

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No interests to declare!

Key question...

To what extent doctors should communicate uncertainty in diagnosis to their patients?



Systematic reviews: what is currently known about the communication of diagnostic uncertainty?

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graph TD; A[Systematic reviews: what is currently known about the communication of diagnostic uncertainty?] --> B[Vignette studies: How do doctors communicate diagnostic uncertainty, and what is the impact of this communication on patients?]; A --> C[Ethnography: How are diagnoses formed, communicated and recorded in acute settings?]; B --> D[Integration of empirical findings with ethical analysis to produce recommendations on how diagnostic uncertainty should be communicated]; C --> D;
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Vignette studies:
How do doctors communicate diagnostic uncertainty, and what is the impact of this communication on patients?

Ethnography:
How are diagnoses formed, communicated and recorded in acute settings?

Integration of empirical findings with ethical analysis to produce **recommendations** on how diagnostic uncertainty should be communicated

What was known about the
topic?

Systematic reviews

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OXFORD

Systematic Review

Diagnostic uncertainty in primary care: what is known about its communication, and what are the associated ethical issues?

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Abstract

Background: Diagnostic uncertainty (DU) in primary care is ubiquitous, yet no review has specifically examined its communication, or the associated ethical issues.

Objectives: To identify what is known about the communication of DU in primary care and the associated ethical issues.

Methods: Systematic review, critical interpretive synthesis and ethical analysis of primary research published worldwide. Medline, Embase, Web of Science and SCOPUS were searched for papers from 1988 to 2020 relating to primary care AND diagnostic uncertainty AND [ethics OR behaviours OR communication]. Critical interpretive synthesis and ethical analysis were applied to data extracted.

Results: Sixteen papers met inclusion criteria. Although DU is inherent in primary care, its communication is often limited. Evidence on the effects of communicating DU to patients is mixed; research on patient perspectives of DU is lacking. The empirical literature is significantly limited by inconsistencies in how DU is defined and measured. No primary ethical analysis was identified; secondary analysis of the included papers identified ethical issues relating to maintaining patient autonomy in the face of clinical uncertainty, a gap in considering the direct effects of (not) communicating DU on patients, and considerations regarding over-investigation and justice.

Conclusions: This review highlights significant gaps in the literature: there is a need for explicit ethical and patient-centred empirical analyses on the effects of communicating DU, and research directly examining patient preferences for this communication. Consensus on how DU should be defined, and greater research into tools for its measurement, would help to strengthen the empirical evidence base.

Key words: Communication education ethics patient-centred care patient–doctor relationship uncertainty

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Communicating diagnostic uncertainty in the acute and emergency medical setting: A systematic review and ethical analysis of the empirical literature

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PMID: 34679138

Abstract

Background: diagnostic uncertainty is ubiquitous. Its communication to patients requires further investigation.

Aims: To determine: 1) What is known about how and why diagnostic uncertainty is communicated in acute care; 2) evidence of the effects of (not) communicating diagnostic uncertainty in the acute setting; 3) associated ethical issues.

Methods: systematic review of Medline, Web of Science and SCOPUS for (acute or emergency care) AND (diagnostic uncertainty) AND (ethics OR behaviours). Critical interpretive synthesis and ethical analysis were conducted.

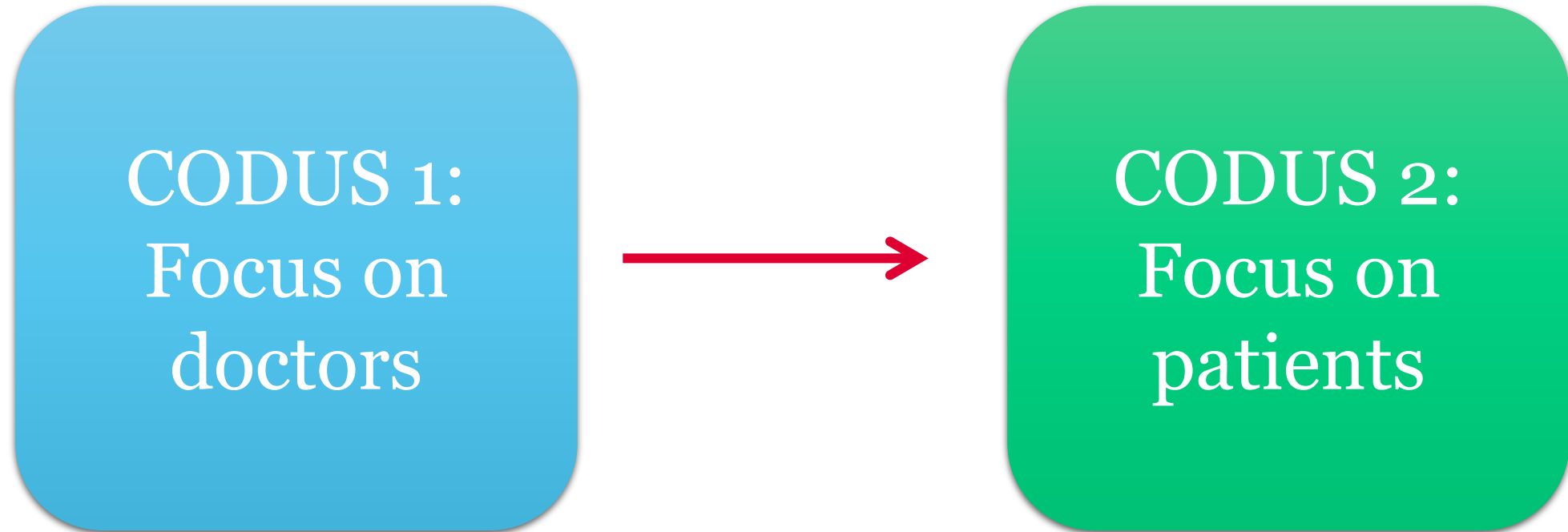
Results and conclusion: Nine studies (primarily surveys and interviews) were identified. Doctors are not trained in communicating diagnostic uncertainty and perceive it to have negative effects on patients; however not communicating diagnostic uncertainty can disempower patients, resulting in delayed/missed diagnoses or inappropriate use of resource.

Key findings...

- Relatively **limited existing research.**
- **Variation in practice:** evidence that diagnostic uncertainty is often **not** fully communicated.
- **Variety of reasons influence decisions** to not communicate diagnostic uncertainty
- We found a **striking lack of patient-focused research.**

Vignette studies

CODUS (Communication of Diagnostic Uncertainty Study): vignette studies



CODUS 1: written vignettes

What did we do? CODUS 1

- **Aims of the study:** i) to characterise variation in doctors' communication of diagnostic uncertainty to patients, and ii) explore why any such variation occurred.
- **Who took part:** 36 doctors working in GIM (general internal medicine) specialties. Participants of a range of grades were recruited by email from 5 English hospitals.
- **Methods:** We developed 4 written vignettes (all common clinical scenarios including significant diagnostic uncertainty). Participants were given each vignette to read in a randomised order, and then asked to tell an online interviewer *exactly what they would tell a typical patient in this situation*. They were then interviewed about reasons for their communication, and about their prior training in communicating diagnostic uncertainty. Interviews were recorded, transcribed and then coded. Quantitative and thematic analysis was undertaken.

Recruitment of participants and screening of inclusion/exclusion criteria

Randomisation of the order in which vignettes will be presented to participant

Read vignette 1 and provide answer to what they would tell a typical patient.

Read vignette 2 and provide answer to what they would tell a typical patient.

Read vignette 3 and provide answer to what they would tell a typical patient.

Read vignette 4 and provide answer to what they would tell a typical patient.

Short semi-structured interview exploring reasons for communication behaviours

Change in bowel habit for 3 years, with normal examination and blood tests

Anaemia and back pain in elderly patient with rheumatoid arthritis on methotrexate

Chest pain in with normal ECG, CXR and bloods

Sudden onset headache with a normal CTH

What did we find?

- Significant **variation** in what different doctors communicated about diagnostic uncertainty, even when presented with identical clinical information.
- Many doctors **did not explicitly acknowledge diagnostic uncertainty** in their discussion with patients, even though they were not 100% certain in the diagnosis being offered. Implicit acknowledgement of uncertainty more common than explicit
- Doctors took **a range of considerations** into account when deciding to communicate, or not communicate, diagnostic uncertainty to patients.
- Almost all doctors reported a **lack of training** in communicating diagnostic uncertainty.

CODUS 2: video vignettes

What next?

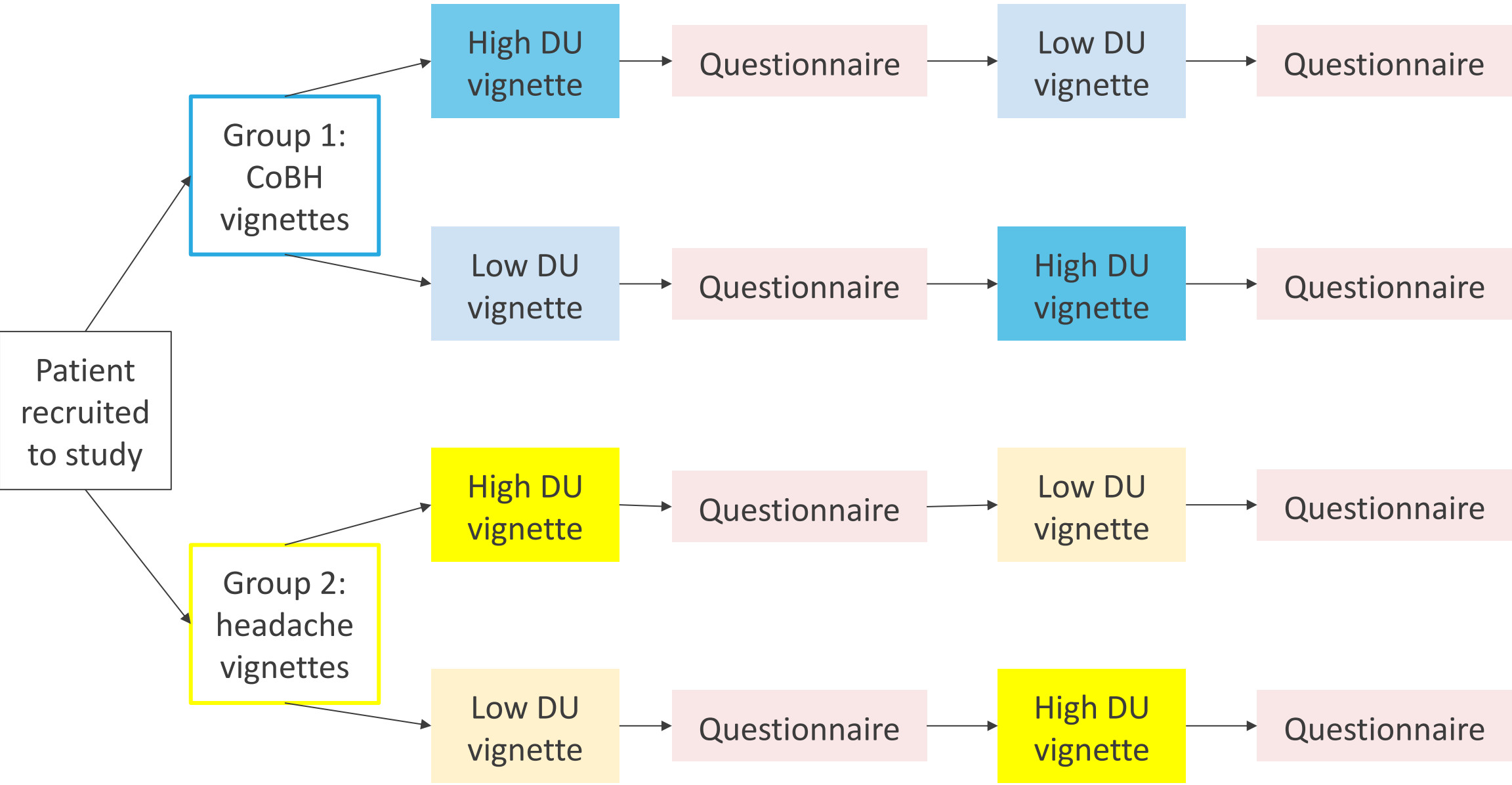
- Building on these initial results, we developed CODUS 2 – a more **patient-focused study!**
- We focused on 2 of the clinical scenarios from CODUS 1, and produced 4 video vignettes showing a doctor talking to camera...



Script	Conditions
V1A	Change in bowel habit, high communication of diagnostic uncertainty
V1B	Change in bowel habit, low communication of diagnostic uncertainty
V2A	Headache, high communication of diagnostic uncertainty
V2B	Headache, low communication of diagnostic uncertainty

What did we do? CODUS 2

- **Aims of the study:** i) determine patient preferences for the communication of diagnostic uncertainty, and ii) examine the effects of communicating diagnostic uncertainty on patients.
- **Who took part:** 111 members of the general public, ages 18 years and over and living in the UK. Doctors and medical students excluded.
- **Methods:** Participants randomised to be in the headache or CoBH group. They then watched two vignettes (either the low communication uncertainty video followed by the high communicated uncertainty video, or vice versa). After watching each video, they completed an online questionnaire. After watching both vignettes, they indicated which they preferred (with a free text box to explain this preference). Quantitative data was analysed using logistic regression and a linear mixed effects model, qualitative data was analysed thematically.





The CT scan also looks for any evidence of bleeding. However, the scan is not 100% reliable at ruling out bleeds. So, in some cases we don't see anything abnormal on the CT, but there's still be a very small bleed. Because of this, in some situations we go on to do a further test, called a lumbar puncture, to more accurately rule in or out whether there has been a bleed.

High communicated diagnostic uncertainty script

The CT scan would have shown us if there were any abnormal findings in the structure of the brain. Importantly, the scan also didn't show any evidence of bleeding within the brain, which is one of the things that we do worry about in these severe headaches.



Low communicated diagnostic
uncertainty script

What did we find in CODUS 2?

- Overall preference for the videos demonstrating **high communicated diagnostic uncertainty**.

The estimated proportion (of the population) preferring videos with high communicated diagnostic uncertainty is **0.64** with a 95% CI [0.55, 0.73].

- Participants found the high communicated diagnostic uncertainty videos significantly more **worrying** for both the headache and change in bowel habit vignettes.

The estimated mean increase in worry from viewing videos with high communicated diagnostic uncertainty is **1.18** with a 95% CI [0.64, 1.72].

- **No statistically significant differences** in other secondary outcomes (such as trust, satisfaction, likelihood of returning to seek medical advice if symptoms worsened/did not improve).

What did we find?

- Free text responses explaining preferences revealed a wide range of considerations – lots of variation in patient views!
- Many participants referred to the following in explaining which video they preferred:
 1. Level of detail/amount of information provided
 2. Ideas about being reassured vs worried by the information
 3. The impact of the communication on the therapeutic relationship
 4. The impact the communication might have on likelihood of returning if symptoms worsened, or on desire for further investigations

“I would prefer to be aware of all of the information - what the doctor is sure of, and what can't be ruled out as well as a more detailed explanations of the risks... Although, of course, the [high communicated diagnostic uncertainty video] **made me feel more worried** I see this as a perfectly normal reaction to such a situation **and I would always rather know the full truth.**”

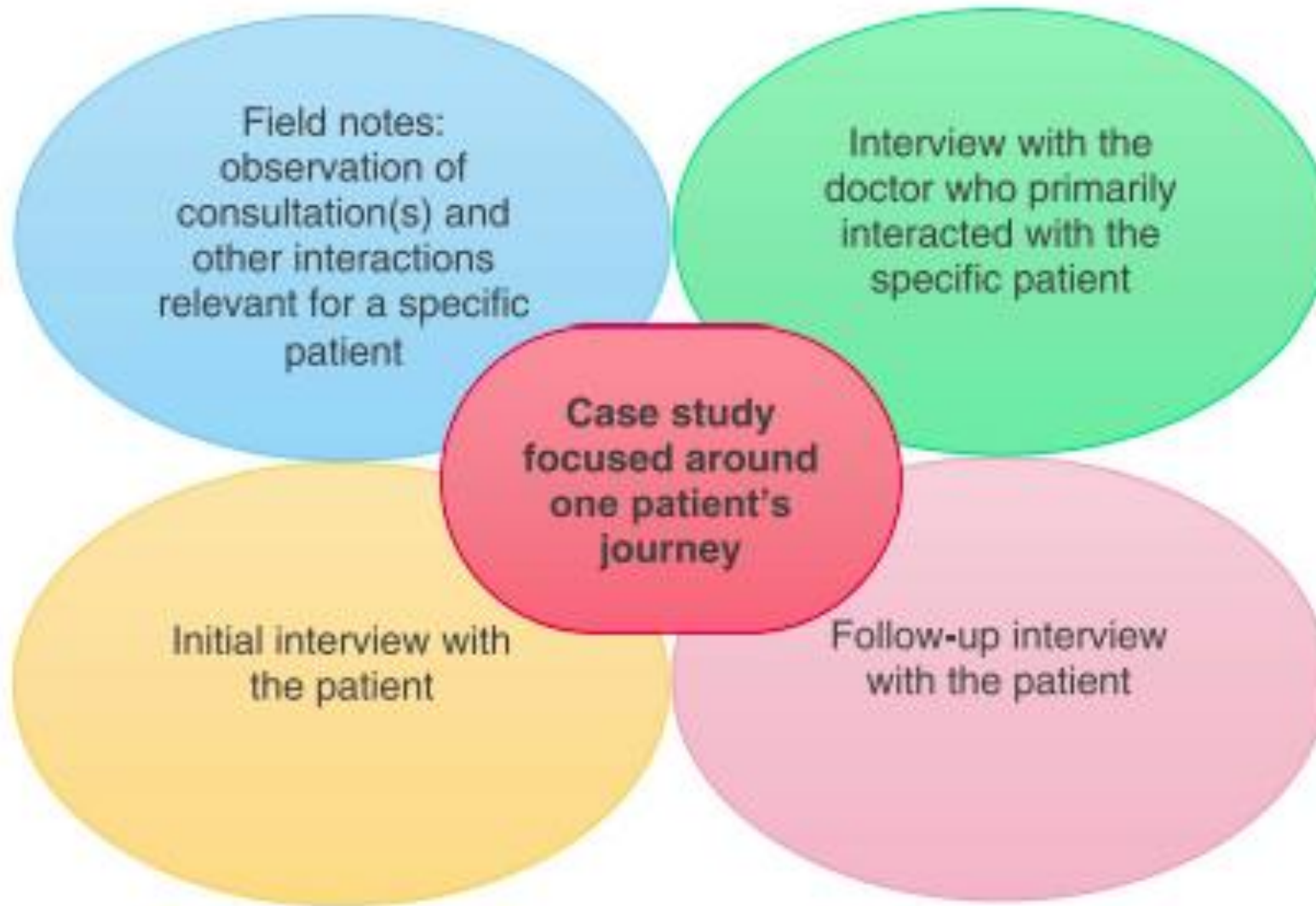
“[A]lthough knowing more about what the 'worst case scenario' might be (and that's a bit scary and more worrying), **I'd rather have the full picture.**”

Ethnography: how are
diagnoses communicated in
practice?

What did we do? Ethnography

- **Aims of the study:** to identify communicative practices facilitating or inhibiting shared understanding between patients and doctors in UK acute secondary care settings.
- **Methods:** Data were collected in acute medical sectors of three English hospitals. Researchers observed doctors as they assessed patients; semi-structured interviews were undertaken with doctors and patients directly afterwards. Patients were also interviewed 2–4 weeks later. Case studies of individual encounters (consisting of these interviews and observational notes) were created. These data were analysed thematically.

---> We conducted 228 h of observation, 24 doctor interviews, 32 patient interviews and 15 patient follow-up interviews.



What did we find?

- We identified communicative practices that seemed to facilitate, or inhibit, shared diagnostic understanding between patient and doctor, revealing three themes:
 - 1) Communicating what has been understood from the medical record
 - 2) Sharing the thought process and diagnostic reasoning**
 - 3) Closing the loop and discharge communication.

Shared understanding was best fostered by clear communication about the diagnostic process, what had already been done and what was achievable in acute settings.

Pulling all of this together...

Impact upon patient perception of doctor

Patient anxiety vs.
reassurance

Information overload

Desire for more investigations



Respect for autonomy

Informed consent

Effective safety-netting

Risk of diagnostic error

Why does it matter?

- GMC (2020) guidance on decision-making and consent states:

*“If you are **uncertain about the diagnosis**, or the clinical effect a particular treatment might have, or if the available evidence of benefits and harms of an option is unclear, **you should explain this to the patient**”*

We have demonstrated...

- **Variation** in how doctors communicate diagnostic uncertainty.
- Doctors **do not always communicate diagnostic uncertainty**, often motivated by a desire to avoid causing patients to worry.
- The majority of patients **prefer greater communication of diagnostic uncertainty**, even if this is slightly more worrying.
- Greater **transparency about the diagnostic process** often resulted in increased doctor–patient shared understanding and increased patient satisfaction.
- When doctors did not explain their diagnostic thinking, patients were more inclined to make **incorrect assumptions about the (differential) diagnosis** or feel as though their concerns had not been addressed.

- Given the majority preference for greater disclosure of diagnostic uncertainty, when faced with a situation where it is not clear how much information a patient might want, **we suggest that doctors should err on the side of greater disclosure of uncertainty information.**
- Patients often **prefer their doctors to communicate transparently throughout the diagnostic process**, even if the acknowledgement of uncertainty and discussion about serious but uncertain diagnoses might induce worry.

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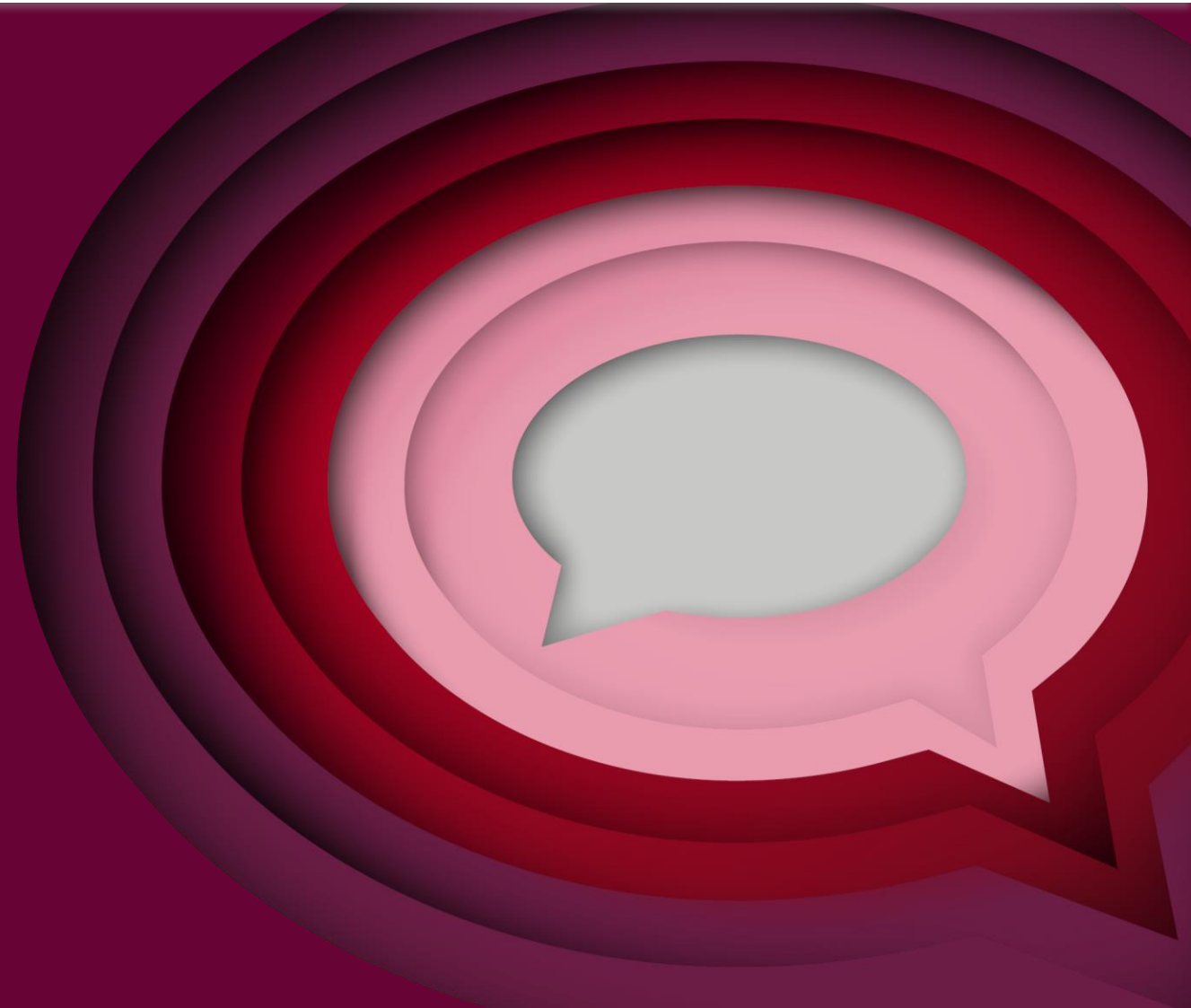
All the doctors, patients and members of
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Looking forward to your questions!

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