'I Wouldn't Know Who to Contact': Insights from Patients with Incurable Head and Neck Cancer to Improve Healthcare Experiences.

Mayland. C.R.,[1, 2, 3] Achinanya, A.,[1] Harrison, M.,[1] Bryant, V.,[4] Payne, S.,[5] Sharp, L.,[6] Hamilton, D.,[7] Patterson, J.[8]

1 University of Sheffield, UK, 2 Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK 3 Palliative Care Unit, University of Liverpool, UK, 4 CHANGE PPI group, Sunderland, UK, 5 Lancaster University, UK, 6 Newcastle University, UK, 7 Newcastle Hospitals NHS Foundation Trust, Newcastle, UK, 8 University of Liverpool, UK
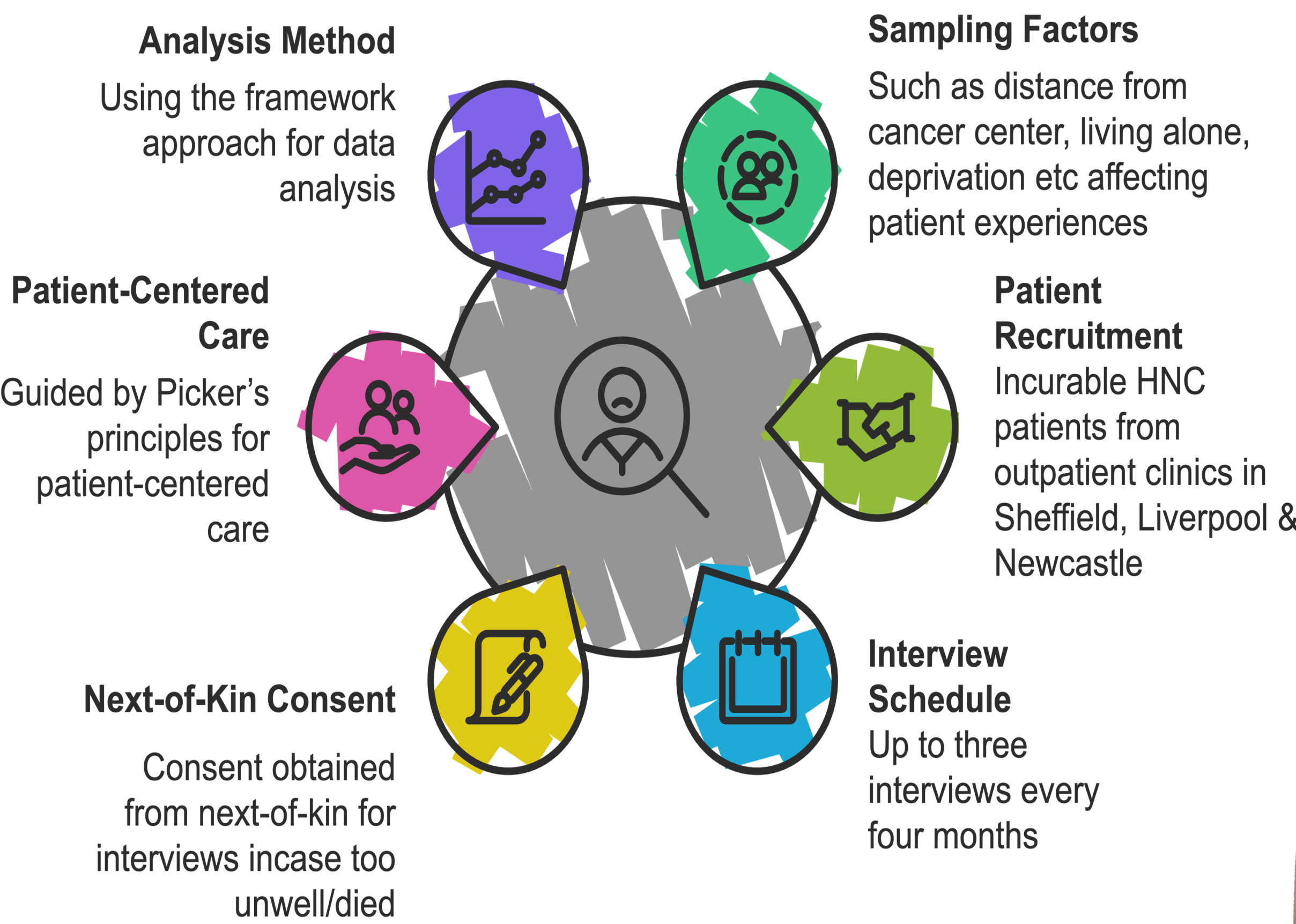
BACKGROUND

One in five people diagnosed with head and neck cancer (HNC) **dies within a year**; for those treated with curative intent, **1 in 10 dies within 12 months**.[1,2] Compared to other cancers, incurable HNC presents a unique and significant symptom burden.[3] The complexity of symptoms and, hence, patients' healthcare needs is markedly greater for incurable HNC compared with other cancers. However, services are currently very centralised and often inequitable.
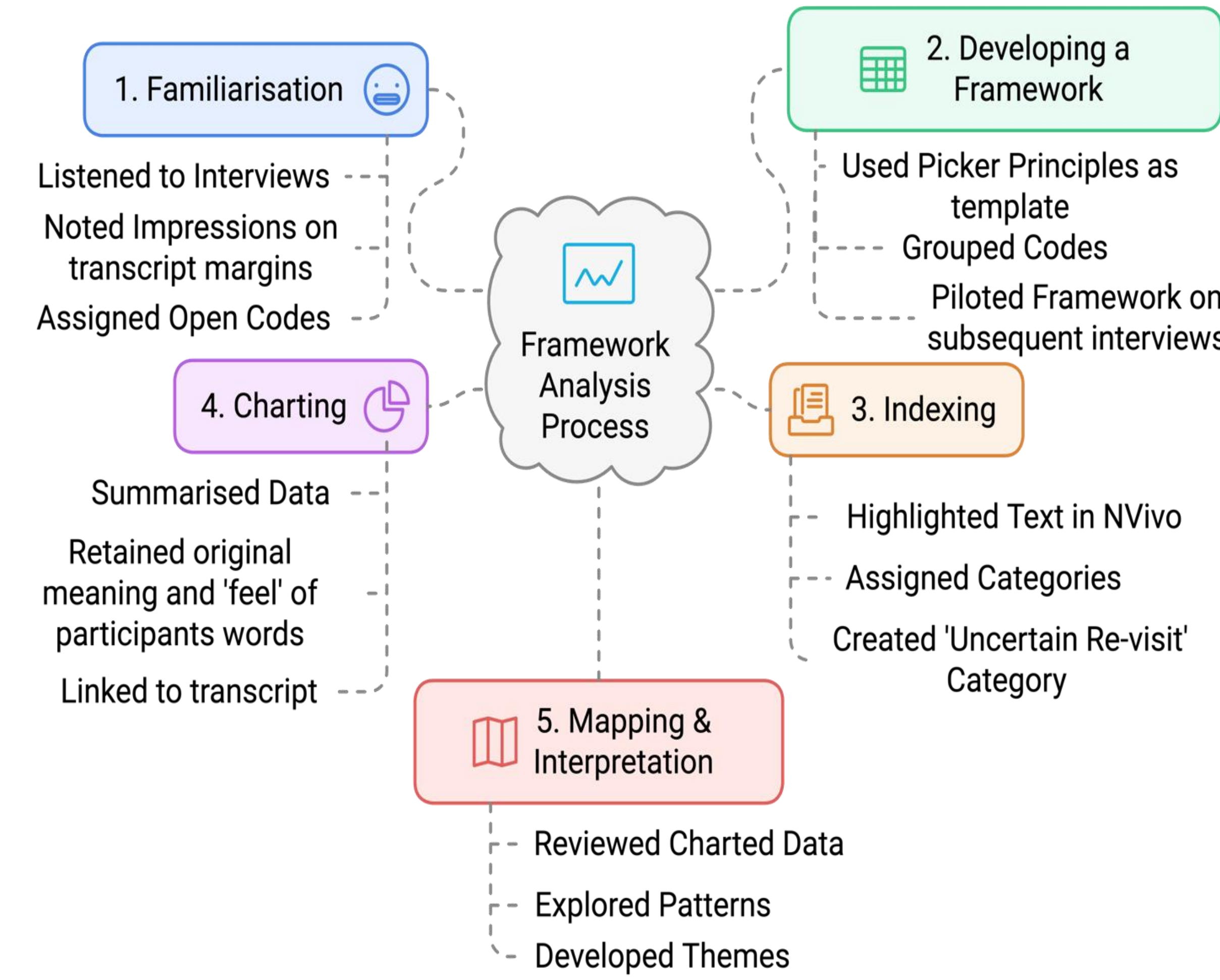
This study sought **to *understand the needs & experiences of incurable HNC patients over time regarding healthcare service use*** and identify solutions for improvement.

METHODOLOGY

Analysis Method
Using the framework approach for data analysis

Sampling Factors
Such as distance from cancer center, living alone, deprivation etc affecting patient experiences

Patient-Centered Care
Guided by Picker's principles for patient-centered care

Patient Recruitment
Incurable HNC patients from outpatient clinics in Sheffield, Liverpool & Newcastle

Next-of-Kin Consent
Consent obtained from next-of-kin for interviews incase too unwell/died

Interview Schedule
Up to three interviews every four months

ANALYSIS PROCESS

The five stages of the framework analysis process were used to analyse serial transcripts.

Framework Analysis Process

1. Familiarisation
Listened to Interviews
Noted Impressions on transcript margins
Assigned Open Codes

2. Developing a Framework
Used Picker Principles as template
Grouped Codes
Piloted Framework on subsequent interviews

3. Indexing
Highlighted Text in NVivo
Assigned Categories
Created 'Uncertain Re-visit' Category

4. Charting
Summarised Data
Retained original meaning and 'feel' of participants words
Linked to transcript

5. Mapping & Interpretation
Reviewed Charted Data
Explored Patterns
Developed Themes

CONCLUSION

Ensuring patients with incurable HNC have consistent points of contact and system navigators can transform their healthcare experience by reducing uncertainty and improving timely support.
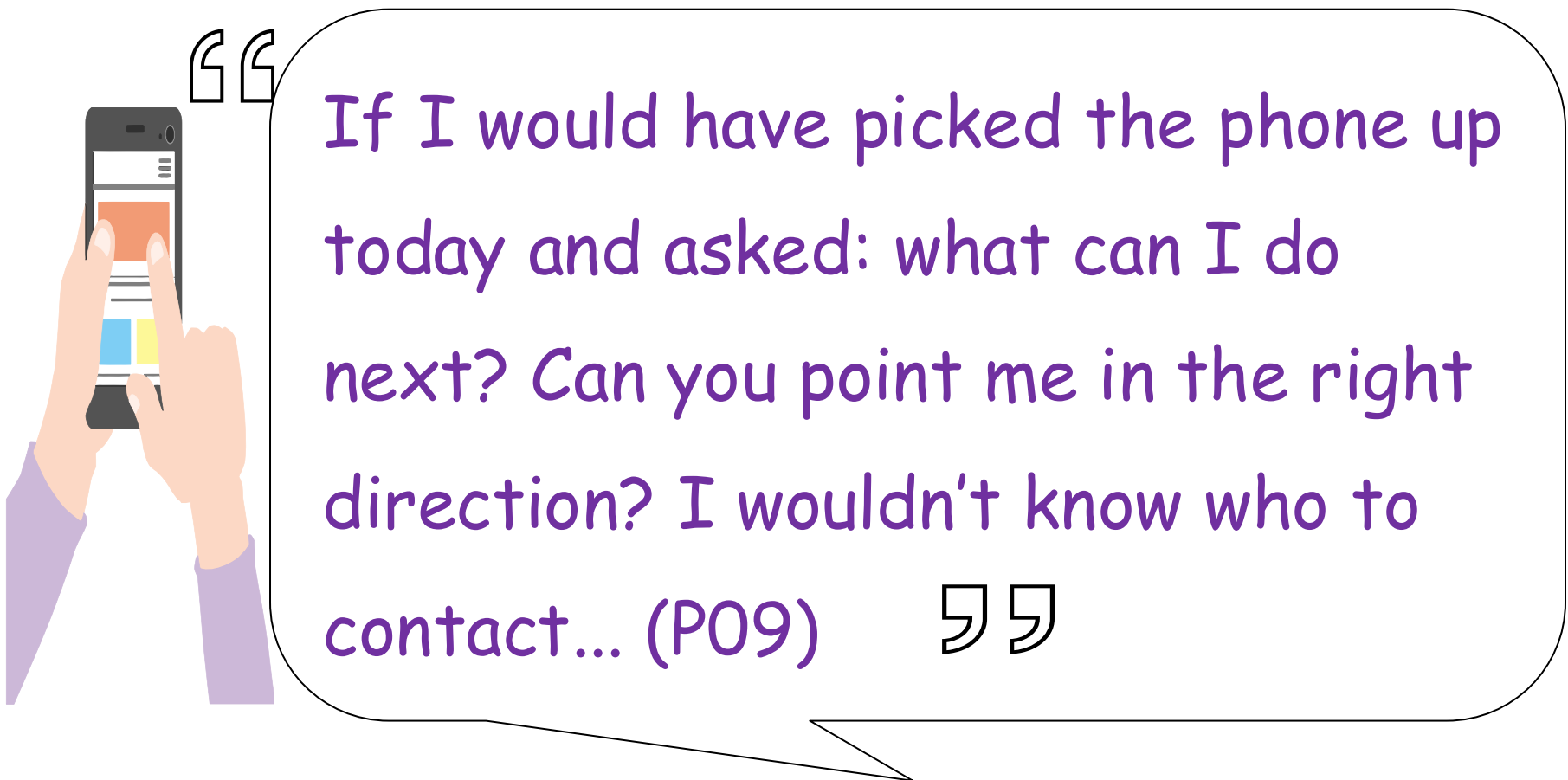
REFERENCES

1. Louie KS et al. Trends in Head and Neck Cancer in England from 1995 to 2011 and projections up to 2025. Oral Onc. 2015; 51(4):341-8.

2. Cancer Research UK. Head and neck cancer incidence over time. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancertype/head-and-neck-cancers.

3. Mayland CR et al. Disease trajectories, place and mode of death in people with head and neck cancer: Findings from the 'Head and Neck 5000' population-based prospective clinical cohort study. Pall Med. 2020; 34(5):639– 50.
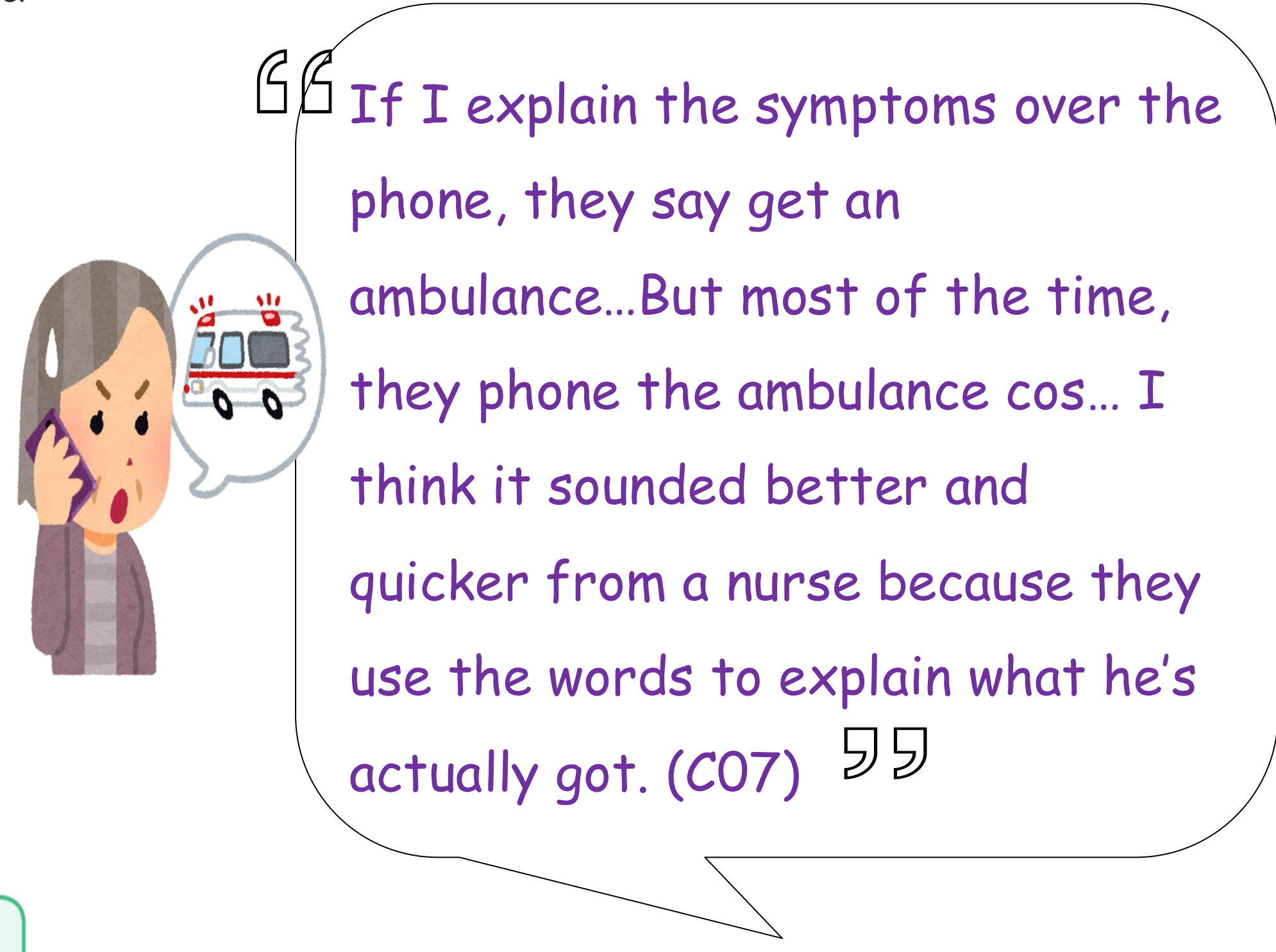
RESULTS & DISCUSSION

Eighteen patients (male=16, 10=<65 years, 17=White British, 9=living alone) and 6 NOK (5=spouse, 1=child) were recruited. A total of 44 interviews were conducted.

THEME 1: CHALLENGES IN EMERGENCY SITUATIONS

Navigating the healthcare system was a key challenge, as **there was uncertainty about who to call**, especially in emergencies when timely support is important.

> If I would have picked the phone up today and asked: what can I do next? Can you point me in the right direction? I wouldn't know who to contact... (P09)
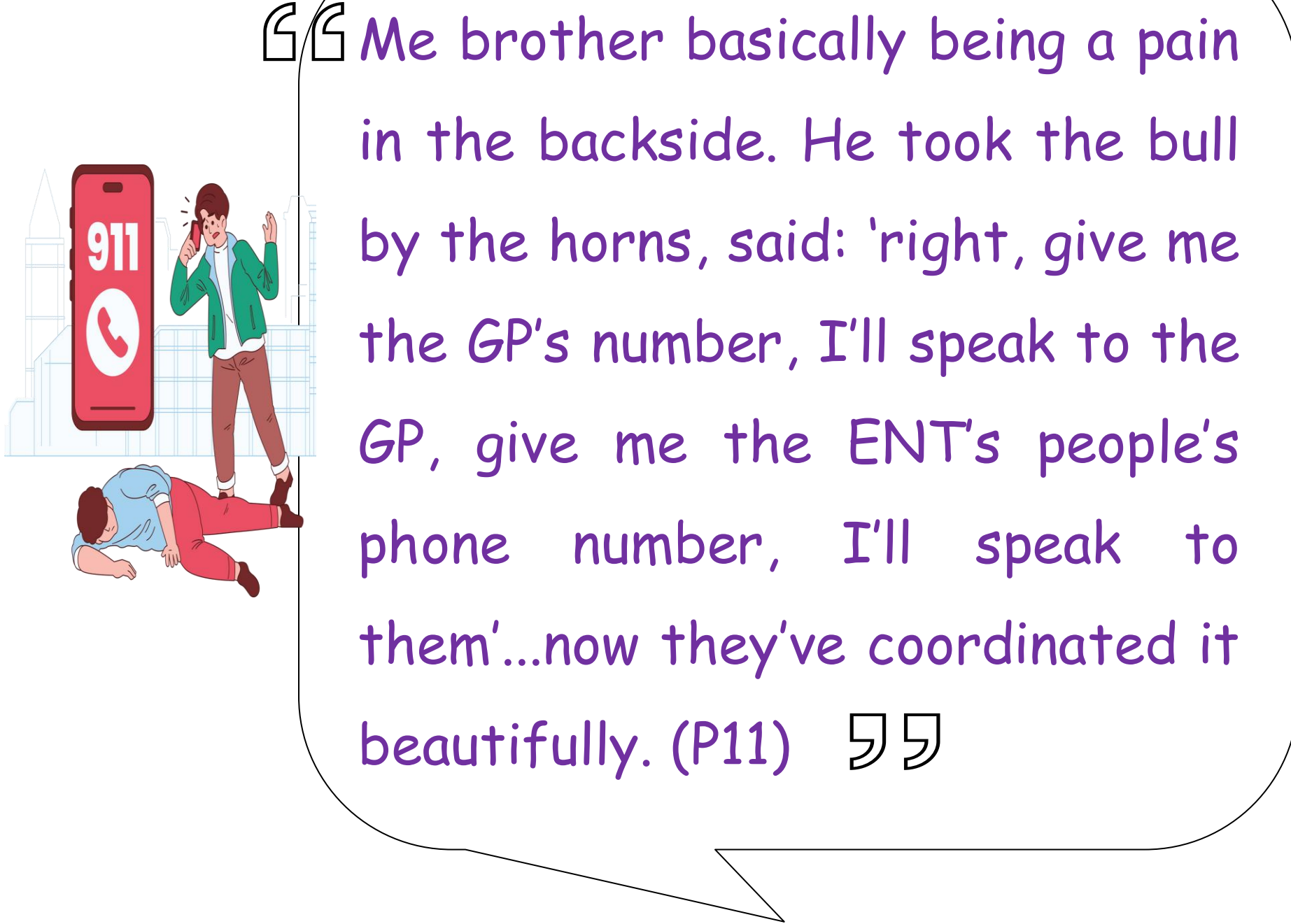
Those with accessible contacts (e.g., key telephone numbers and the ability to use alternative communication such as WhatsApp) helped with signposting.
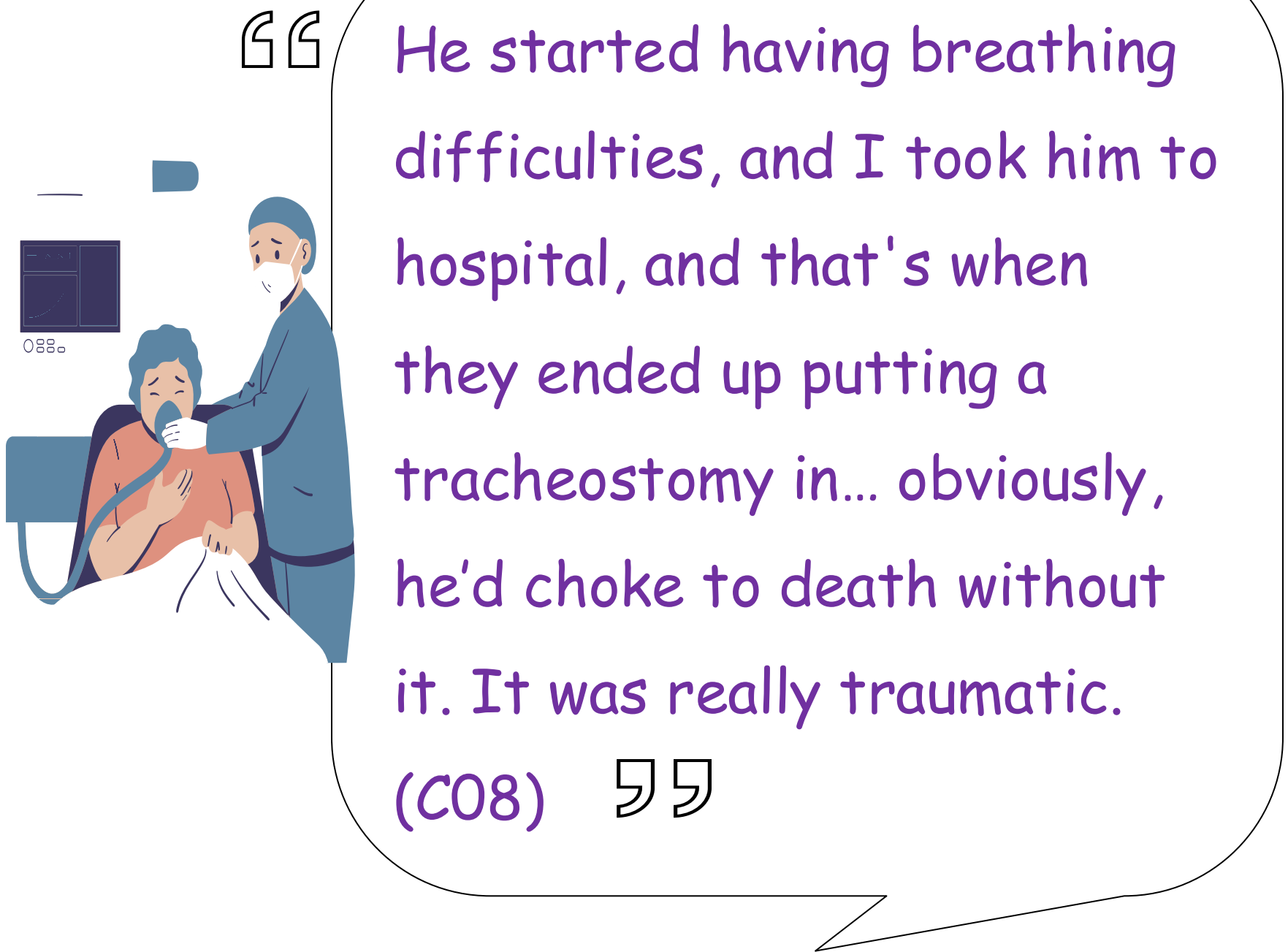
> If I explain the symptoms over the phone, they say get an ambulance...But most of the time, they phone the ambulance cos... I think it sounded better and quicker from a nurse because they use the words to explain what he's actually got. (C07)

THEME 2: NEED TO IMPROVE HEALTH LITERACY

Key advocates (e.g., specialist nurses and family members) **were vital** in improving health literacy and health system navigation.

> Me brother basically being a pain in the backside. He took the bull by the horns, said: 'right, give me the GP's number, I'll speak to the GP, give me the ENT's people's phone number, I'll speak to them'...now they've coordinated it beautifully. (P11)

Certain clinical situations, such as breathing difficulties, meant the hospital was the most appropriate care environment.

> He started having breathing difficulties, and I took him to hospital, and that's when they ended up putting a tracheostomy in... obviously, he'd choke to death without it. It was really traumatic. (C08)

IMPLICATIONS FOR POLICY & PRACTICE

❖ Policies should focus on providing HNC patients with centralised contact points and system navigators and integrating digital tools like WhatsApp to ensure timely access to support.

❖ A coordinated, multidisciplinary approach, with an emphasis on improving health literacy, is crucial for addressing the complex needs of HNC patients.

ACKNOWLEDGMENT

> To listen to the patient stories of their healthcare experiences, scan the QR codes below.

Contact: Dr. Ada Achinanya, a.achinanya@sheffield.ac.uk