*Original Research Article*

Journal of Primary Care & Community Health
Volume 17: 1–11

DOI: 10.1177/21501319261466432
journals.sagepub.com/home/jpc
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# Caring for Adults with Congenital Heart Disease in Primary Care: A Qualitative Study of Generalist Health Care Professionals' Experiences

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## Abstract

**Objective:** To explore how primary and community-based healthcare professionals (HCPs) experience supporting adults with congenital heart disease (ACHD) in generalist healthcare settings. **Methods:** A qualitative interpretive study was conducted with 18 UK primary care HCPs, including general practitioners and advanced clinical practitioners. Semi-structured interviews were analysed using reflexive thematic analysis. **Results:** An overarching theme, *balancing knowledge, care and constraint*, captured how HCPs supported adults with ACHD while navigating uncertainty, relational responsibility and fragmented systems. Three interconnected themes were identified: *navigating uncertainty*, reflecting limited ACHD knowledge and infrequent exposure; *sustaining relationships*, highlighting the role of continuity and familiarity in maintaining care; and *working around the system*, describing how participants adapted to unclear pathways, inconsistent communication and organisational constraints. Despite limited condition-specific knowledge, participants described recognising concerns, coordinating care and sustaining continuity across fragmented services. **Conclusion:** As increasing numbers of adults with ACHD receive care beyond specialist centres, primary and community-based HCPs play a crucial role in recognising concerns, coordinating care and maintaining continuity. Participants' accounts highlight the often-unseen relational and coordinating work required to keep patients connected to appropriate care despite uncertainty and organisational constraints. Strengthening ACHD care therefore requires more than condition-specific education; it depends on healthcare systems that facilitate communication, collaboration and shared responsibility across specialist and generalist services.

## Keywords

community health, qualitative methods, primary care, adult congenital heart disease, long-term care

Received: 30 April 2026; Revised: 18 June 2026; Accepted: 22 June 2026

## Introduction

Once associated with high childhood mortality, congenital heart disease (CHD) is now increasingly recognised as a lifelong condition, with advances in medical care contributing to a growing and ageing adult population.[1,2] As this population ages, rates of multimorbidity, healthcare use and associated costs continue to rise.[3,4] Health systems increasingly seek to manage

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such long-term conditions in community and primary care settings (first-contact, community-based services within the National Health Service (NHS)), reflecting policy aims to deliver care in "the right place, at the right time, by the right person".[5]

As care increasingly extends beyond specialist centres, healthcare professionals (HCPs) working within community and primary care settings are often the first point of contact for adults with congenital heart disease (ACHD) and play an important role in coordinating access to specialist services.[6] Lifelong specialist follow-up is a central component of ACHD care, yet discontinuity of follow-up remains a recognised challenge and lack of specialist care has been associated with increased morbidity and mortality.[6,7] As care increasingly spans specialist and generalist services, primary and community-based HCPs may play an important role in recognising gaps in care, enabling continuity and helping patients remain connected to specialist services.

However, many of these HCPs encounter ACHD infrequently and may have limited condition-specific training or experience.[8] This creates a challenge within generalist practice, where HCPs are required to facilitate care for patients with complex cardiac and non-cardiac needs while navigating unclear referral pathways, fragmented communication and the demands of continuity in long-term care.[8-12]

While patient and specialist perspectives have been explored, little is known about how primary and community-based HCPs experience caring for adults with CHD. These HCPs occupy a pivotal yet underexamined position within the care continuum, negotiating not only clinical complexity but also uncertainty, responsibility and system pressures. This study addresses this gap by exploring how HCPs in out-of-hospital settings perceive and navigate the challenges of ACHD care, with a focus on how knowledge, relationships and organisational context shape practice when managing an infrequently encountered but clinically complex condition.

## Methods

### *Study Design and Methodological Orientation*

This study adopted a qualitative interpretive design to explore how HCPs experience and navigate the provision of care for adults with CHD in primary care. An interpretivist epistemological stance underpinned the study, recognising that participants' accounts are shaped by social, relational and organisational contexts, and that meaning is co-constructed between researcher and participant.

Reflexive thematic analysis (RTA), as developed by Braun and Clarke (2022),[13] provided the methodological framework for exploring patterns of meaning across participants' accounts and supported both descriptive and interpretive engagement with the data. This approach was chosen for its suitability in exploring under-researched experiential domains and its capacity to enable both descriptive and interpretive analysis.

### *Setting and Participants*

Participants were HCPs working in United Kingdom (UK) primary care settings and included general practitioners (GPs) and advanced clinical practitioners (ACPs). These roles were selected as they represent key points of contact for adults with CHD outside specialist services.

A purposive sampling strategy was used to capture variation in factors shaping HCPs' experiences of ACHD care. This included professional role, clinical experience, exposure to ACHD and practice context (including rural or urban setting, socioeconomic deprivation and proximity to specialist services). Participants were also recruited across a range of career stages, enabling exploration of how experience may shape perspectives on ACHD care. These factors were considered because of their potential influence on access to expertise, referral pathways and continuity of care. Recruitment was facilitated through NHS primary care networks representing clusters of general practices and professional contacts. Inclusion criteria were: (1) registered HCPs working in primary care settings, (2) first point of contact for patients.

Eighteen participants were recruited, comprising 11 GPs and 7 ACPs (including nurses, physiotherapists and occupational therapists). Participants had between three months and over 30 years of experience in primary care. Recruitment continued until the dataset was judged to provide sufficient depth, richness and diversity to address the research question. This approach was informed by the principle of information power,[14] whereby sample size is determined by the study aim, sample specificity, quality of dialogue and analytic strategy, rather than by a predetermined numerical target. Consistent with Braun and Clarke's reflexive thematic analysis, sample adequacy was considered in relation to the generation of rich and meaningful interpretations.

### Data Collection

Data were generated through semi-structured interviews conducted between July 2022 and May 2024. Interviews were undertaken virtually via video conferencing to facilitate participation across geographically dispersed sites. Interviews lasted between 30 and 90 minutes.

An interview guide (Appendix 1) was developed through review of the adult congenital heart disease (ACHD), primary care and continuity of care literature, alongside the clinical and lived experience of the research team. The guide was further informed by patient and public involvement (PPI) contributors with lived experience of ACHD, who provided feedback on the relevance, clarity and scope of the topics explored. Questions focused on participants' experiences of caring for adults with ACHD, perceived challenges, communication with specialist services, care coordination and support needs. The interview guide was tested with primary care healthcare professionals and subsequently refined iteratively throughout the study to improve question clarity, flow and relevance. In line with RTA, the guide was used flexibly to enable participants to introduce issues they considered important to their practice.

All interviews were conducted by the first author (SE). Field notes were recorded following each interview to capture contextual observations, initial interpretations and methodological reflections. Interviews were audio-recorded, transcribed verbatim using transcription software, and checked for accuracy against the original recordings. All transcripts were anonymised prior to analysis.

### Data Analysis

Data were analysed using Braun and Clarke's six-phase reflexive thematic analysis.[13] Transcripts were read repeatedly to facilitate familiarisation with the data before open line-by-line coding was undertaken by SE. Coding was initially semantic, before moving towards more latent and interpretive coding as patterns of meaning were developed. The research team met regularly to explore interpretations, challenge assumptions and facilitate reflexive analytic development. Consistent with RTA, these discussions were intended to deepen interpretation rather than achieve coding consensus.

Codes were then organised into candidate themes through active engagement with the data considering patterns of shared meaning and underlying conceptual coherence. Themes were refined through ongoing comparison within and across transcripts to ensure they were internally coherent, distinct and meaningful. To enhance analytic transparency, Table 1 provides examples of how participants' accounts were interpreted during analysis, showing the progression from data extracts to coding and theme development. Analysis moved beyond descriptive coding to develop an interpretive understanding of the data. A thematic map was generated inductively throughout analysis to support exploration of patterns of shared meaning and the development of themes.

### Reflexivity and Researcher Positioning

Reflexivity was integral to the study. The lead researcher (SE) is a community-based registered nurse with lived experience of ACHD, which informed engagement with participants and interpretation of the data. Reflective journalling was used throughout the study to support ongoing examination of assumptions and researcher positioning. Participants were provided with information about the study and the researcher's professional background prior to interview. The researcher's personal experience of ACHD was not routinely disclosed during interviews.

### Rigour and Trustworthiness

Rigour was supported through prolonged engagement with the data, iterative analysis, clear documentation of analytic decisions and the use of rich illustrative quotations. Detailed descriptions of the study context and participants enable readers to assess the transferability of the findings. The study was reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ).[15]

### Ethical Considerations

Ethical approval was obtained from Health and Care Research Wales (REC reference 22/PR/0370). All participants received written information about the study and provided informed consent prior to participation. Confidentiality was maintained through anonymisation of transcripts and removal of identifiable information. Participants were reminded that involvement was voluntary and that they could withdraw at any time without consequence. Given the potential for discussing emotionally

**Table 1.** Coding Framework

| Q | Label | Summary of meaning |
|---|---|---|
| **Theme 1 navigating uncertainty** | | |
| **Q1** | Epistemic uncertainty in generalist practice | Awareness of limits of knowledge; "not knowing what you don't know" |
| **Q2** | Lack of formal education and training | Absence of undergraduate/postgraduate preparation |
| **Q3** | ACHD positioned as a paediatric condition | Limited recognition in adult primary care training |
| **Q4** | Infrequent exposure and experiential knowledge gaps | Rare encounters; knowledge based on isolated cases |
| **Q5** | Holistic generalist care and non-compartmentalisation | Whole-person care; conditions not treated in isolation |
| **Q6** | Risk management and referral under uncertainty | Safety-first approach; low threshold for referral |
| **Q7** | Perceived complexity and emotional burden | Intimidation, anxiety, limited confidence |
| **Q8** | Patient expertise and shared care | Patients as knowledgeable partners in care |
| **Theme 2 sustaining relationships** | | |
| **Q9** | Professional responsibility and commitment to care | Motivation to act; "doing the right thing" |
| **Q10** | Vulnerability and barriers to access | Housebound patients; difficulty engaging with care |
| **Q11** | Risk of loss to follow-up | Lack of recall systems; patients falling through gaps |
| **Q12** | Relational continuity and knowing the patient | Familiarity; recognising change over time |
| **Q13** | Fragmentation across services and systems | Disjointed care; transitions and service boundaries |
| **Q14** | Relational work to maintain continuity | Follow-up, checking, keeping patients visible |
| **Theme 3 working around the system** | | |
| **Q15** | Adaptive workarounds in care coordination | Informal strategies to "make the system work" |
| **Q16** | Uncertainty in pathways and access to specialist care | Lack of clear referral routes or guidance |
| **Q17** | Breakdowns in communication and information flow | Missing, delayed, or unclear information |
| **Q18** | Value of clear specialist guidance | Detailed letters improve clarity and confidence |
| **Q19** | System pressures and constraints on care delivery | Time, workload, funding pressures |
| **Q20** | Evolving understanding of ACHD as lifelong care | Shift from "fixed" to chronic condition |
| **Q21** | Need for education, pathways and specialist support | Training needs; system-level improvements |

Q9 was conceptualised as a bridging code across Themes 1 and 2, capturing how professional responsibility links individual decision-making under uncertainty with relational continuity in primary care.

challenging experiences, interviews were conducted sensitively, with participants offered the opportunity to pause or stop at any time.

## Results

The overarching theme of balancing knowledge, care and constraint captured how primary care professionals sought to deliver person-centred care for adults with ACHD while negotiating uncertainty, emotional strain and fragmented systems. This theme reflects how they navigated tensions between limited knowledge, relational responsibility and system constraints in everyday practice. Despite limited training and inconsistent specialist input, participants demonstrated adaptability and a strong sense of professional responsibility. Three interrelated themes illustrate this balance: navigating uncertainty, sustaining relationships, and working around the system. The themes and illustrative participant quotations are summarised in Table 2.

### *Theme 1: Navigating Uncertainty - You Don't Know What You Don't Know Q1*

Participants consistently described limited education and clinical exposure to ACHD, shaping both their confidence and emotional experience. Most had received little or no formal training during undergraduate or postgraduate study, learning instead through chance encounters, hospital correspondence or self-directed research (Q2). For many, ACHD was still perceived as a paediatric issue rather than a condition encountered in adult primary care (Q3). Infrequent exposure meant that knowledge often rested on isolated cases, with HCPs relying on analogy rather than structured understanding (Q4). Within this context, participants positioned ACHD within the broader scope of generalist care, describing how patients were often seen for non-cardiac issues and could not be separated into discrete conditions. This reinforced the need for a holistic

**Table 2.** Illustrative Quotations

| | Illustrative quotations and data themes | |
|---|---|---|
| Q1 | it's not what you know it's knowing or rather not knowing what you don't know… I feel fairly confident that I don't… or rather I know what I don't know what I don't know if that makes sense. | HCP 07 |
| | Really there's a few things GPs. Skate on extremely thin ice so we have to know a bit about most things. | HCP 10 |
| Q2 | I can't remember having had any training either specifically throughout my career or as a medical student on adult congenital heart disease... Nothing specifically that I can remember pertaining to the over eighteens or anything that would particularly inform what I do now in primary care. | HCP 06 |
| | I certainly don't recall any training about adults with congenital heart disease, treated or untreated. | HCP 10 |
| | No, we have not done the education around the needs of this group. | HCP 01 |
| | the majority of even generally experienced GPs have limited knowledge about these patients conditions and you know the risks and the follow up that's needed really as well. | HCP 06 |
| Q3 | The only training that had around congenital heart disease was in paediatrics… There has been limited exposure maybe in my paediatrics rotation… but not in adults? Absolutely none. | HCP 11 |
| Q4 | It's so definitely an area where I'm not very, you know. I don't know much about at all, basically, so yeah, I wouldn't be very confident at all in that area. And I would say that I don't really have very much knowledge at all about it. | HCP 13 |
| | Because I don't feel it's something I see so commonly it just doesn't stick I might see someone every few years. | HCP 03 |
| | I've had none in GP practise. Probably only coincidentally come across it in a patient's past medical history rather than been involved in any management or investigations, or their potential treatment or management plans. So very little. | HCP 08 |
| | I don't think I can remember the last time I saw an adult with congenital heart disease or knowingly saw an adult in primary care with congenital heart disease | HCP 04 |
| | No, I can actually only recall seeing one… but apart from that, no, I can't really recall having much input or dealing with that side of things. | HCP 03 |
| Q5 | we wouldn't often be very much directly involved in their care, but they'll be coming to us for other things like contraception or something like that. | HCP 09 |
| | it all blurs together because obviously it's one person you can't split them into physical health and mental health. | HCP 02 |
| | it might be just helpful to try and push that further, maybe we'll just to promote it a bit further or you know like, raise awareness really of congenital heart disease | HCP 13 |
| Q6 | I would probably start with a referral to the cardiology clinic at the local hospital. I would probably organise some investigations perhaps referring for an ECHO ECG some bloods chest X-ray things like that. | HCP 01 |
| | They would be a higher risk, but it's it's knowing it's having more, you know, yeah, they've got a heart, a chance of a heart thing. But they they what to what level you know what? How how does that affect them but they are in generally I would say they are higher risk than normal you know norm | HCP 18 |
| | I would just go general cardiology… I don't know if there's somebody specific. | HCP 16 |
| | I would know that there is a hospital I'm supposed to send them to. I'd have to go and hunt what it was. But I do know that there's an adult congenital heart disease service. I think it's in [place] isn't it?" | HCP 05 |
| | I probably haven't seen enough that I would say I'm confident in dealing with complications or confident in dealing with untreated congenital heart disease, other than being aware of sometimes the signs to look out for | HCP 4 |
| | If they were very unwell, I'd get them up to hospital… but even if it wasn't that bad, I'd still probably go via advice and guidance first… maybe refer but ask for advice at the same time, just to be safe. | HCP 16 |
| Q7 | I think I think these patients are very almost intimidating to look after… We tend to worry about well personally I'm using we actually I worry I worry about missing a diagnosis… it's a very, very challenging area to feel confident at | HCP 11 |
| | Yes, they they're complicated. A lot more complicated | HCP 12 |
| | I think these worries are more when you're more when you're more junior in your career. I'm not saying now I I feel more confident, but now I'm a bit more well versed in it because of the experiences I've had. | HCP 11 |
| | …it was the particular group that opened my eyes to the fact that the science is far, far more complicated than you might like it to be. | HCP 10 |
| | These aren't your bread-and-butter cases… you're not dealing with them regularly and it's difficult to find time to keep up with everything….. We could do with sessions or updates, but realistically it's hard to fit that in. | HCP 06 |
| Q8 | "She's very knowledgeable about her own conditions. She probably has a good idea of who she asks about what…..They're very informed, sometimes they tell you what they can and can't take." | HCP 09 |
| | You need to empower patients to do, to do the most for themselves and make sure they don't go on to develop type 2 diabetes on top of whatever they've got, you know, or make sure they've got good heart health and they're exercising appropriately so there is something about the patient taking that responsibility | HCP 11 |
| | I'm more open to asking the patient's experience and understanding and asking them what do Sats [oxygen saturations] usually run at, what what's your blood pressure usually like because this seems abnormal for me. Often the patients are able to tell you more about the condition than you than you know. | HCP 11 |
| | The letter was… very much. This is normal for the patient. Don't panic. Don't give them oxygen. That's normal for them. | HCP 12 |

*(continued)*

**Table 2.** (continued)

| | Illustrative quotations and data themes | |
|---|---|---|
| Q9 | "Think most of us in primary care will feel a bit apprehensive." | HCP 03 |
| | We're quite good in general practise. We'll try and do what we can for patients in primary care… we like to keep hold of our patients. We like to manage them… continuity of care is important to us… yeah, we're kind of taking that responsibility for them. | HCP 11 |
| | you've obviously got a lower threshold to treat, with the background | HCP 07 |
| | My job is to recognise when the person needs referrals, not a good idea for a doctor to be everything to everybody | HCP 10 |
| Q10 | …little bit concerned about the patients that are unable to come in for their annual reviews in surgery and that actually are housebound or learning difficulties that can't come in that might have some chronic conditions | HCP 01 |
| Q11 | …experience has been generally poor follow up once these patients' transition | HCP 06 |
| | Like perhaps a QOF registered, but some kind of register where then they wouldn't get lost. And there'd be a alike a protocol from primary care to make sure they were followed up. | HCP 03 |
| | They don't fit into a category that then gets recalled on a regular basis… other than from their medication. But you can't put congenital heart disease or asthma or something that then triggers an annual recall. | HCP 05 |
| | If there wasn't a register and the doctors didn't know these people, how do you know even existed? | HCP 2 |
| | my worry is the people who fall off the list because they left paediatrics… those are the group that's lost… quite a lot of them will probably have been lost. | HCP 10 |
| | I guess a very clear letters with long term plans make life easier, given people get lost. But some way of sort of staying in touch with patients sort of get them to respond on an annual basis to an email with some up to date. | HCP 05 |
| Q12 | We've got a handful of patients with congenital heart disease, and you do tend to know them well because they've been with us for years. That's helpful… you get to know what's normal for them. | HCP 06 |
| | bit of gut feelings, knowing something's not quite right… | HCP 07 |
| Q13 | think funding should go into secondary care sector to find them from previous records | HCP 10 |
| | Sometimes people… if they move practices… kind of fall off somewhere | HCP 16 |
| | the system splits them into parts. You go and see this person for this, and you see this person for this | HCP 02 |
| Q14 | And I'll phone them back and I'll say, oh, I've read this letter. Then, you know, did anything happen from that, that consultation with the cardiologist? What did they just say? | HCP 16 |
| Q15 | I would maybe if I think they needed referral I'd probably refer but then ask for some advice and guidance first because I was thinking if there's things I could do in the meantime while I'm waiting for them to see a specialist, then I might as well get them done really. | HCP 16 |
| Q16 | I'll say let me just get through your notes, I haven't got time just now, I'll phone you back | HCP 16 |
| | I'd refer to general cardiology and hope it gets to the right team. | HCP 13 |
| | no specific pathway that's followed……it's really difficult | HCP 06 |
| | …share your expertise, that's key across all services. Services still work in silos. We're not joined up properly and that's why we have these specialist areas, and we think that as general practise or general practitioners, we have to go to that specialist area, share that knowledge because those specialist groups are often saturated as well with patient contacts. And maybe if that was shared… then, you know, that would not only release some of the burden, but it would also develop us and our level of patient care | HCP 8 |
| | If they've got acute chest pain there's the rapid access chest pain clinic, but if it's congenital, I don't really know. I'd probably use advice and guidance, but that's general cardiology, not congenital. | HCP 16 |
| | what what's the pathway… what should I be looking for… do I need to refer on… what do I do with this patient that has maybe has symptoms that need to be reviewed? | HCP 18 |
| | for congenital heart disease, I think it would be tricky to come up with a pathway because there are so many different ones… I think what might be helpful… is having maybe a contact line for advice. | HCP 12 |
| | I haven't really come across it, or I haven't come across any pathways that kind of thing yet. | HCP 13 |
| Q17 | we can clearly see we have not had several of the letters… you're trying to puzzle it out… and you can't understand… it's not logical. | HCP 09 |
| | just very, very clear to us about what you want us to do… clear letters and clear instructions. That you pay at the end of the letter would be perfect. | HCP 09 |
| | Often the hospital picking them up will. It'll be the GP they'll contact for the previous letters. We have this all the time. | HCP 09 |
| Q18 | they had a very detailed letter from a consultant cardiologist about what to expect, how to manage cases, how to manage complications. | HCP 12 |
| | key letters from specialists giving a long-term plan and advising us on what we should look out for | HCP 05 |
| | You get something saying I need to see them back in three years…you just know it's not going to happen. Either the contact details have changed, or the letter never arrives. You end up chasing, and it takes ages to find out what's actually happening. | HCP 05 |

*(continued)*

**Table 2.** (continued)

| | Illustrative quotations and data themes | |
|---|---|---|
| Q19 | needs to be an understanding of what is in the primary care contract and the Community care team contracts and what we will do and why because often more and more with pressures from secondary care we are asked to do more without additional funding | HCP 11 |
| | we have 10-minute appointments and you're going through all these letters, and you can't understand… it's not logical" (HCP09) | HCP 09 |
| | It can become a bit of a tick box thing…….. Sometimes because that's the way the system is and there has to be a system, it takes away from the fact that this is meant to be helpful to the patient, not just so the surgery can get the money, and it's important the surgery gets the money in to be able to continue to provide a service. | HCP02 Added |
| | workload. That's the first thing, and it's not you know, it's not only clinical work, it's admin workload as well. Yeah, you know, and so it's right. The way across the board. I think that would be the first impact. I think that's the main impact, really | HCP 07 |
| | 10 minutes is grossly unsafe to do pretty much anything, actually… if you give somebody 100 things to do in 10 minutes, don't be surprised when they don't do most of them… the more things you try and cram into a consultation, the more dangerous it is | HCP 10 |
| Q20 | things have changed a lot in the last nearly 40 years… we used to be taught that you mended someone's congenital whatever it was, and that was it. They were fixed. | HCP 10 |
| Q21 | I think what might be helpful… is having maybe a contact line for advice… it might be helpful to have a point of contact if we encounter some more with congenital heart disease, you know, to seek some specialist advice. | HCP 12 |
| | there is a gap in my knowledge regarding that… training would be invaluable, I think… what should I be looking for… do I need to do anything about it? Do I need to refer on… pathways… | HCP 18 |
| | it would be helpful to have a teaching from a specialist nurse or specialist team… and kind of a… direct person to how to manage and look after them properly. | HCP 13 |

approach, even when condition-specific knowledge was limited (Q5), highlighting both the complexity of ACHD and their limited confidence in managing it (Q7). Uncertainty carried an emotional toll. Many described feelings of anxiety, guilt and discomfort related to their limited knowledge, alongside concerns about their ability to provide appropriate care (Q7). In response, some HCPs adopted risk-averse approaches, referring more readily for reassurance (Q6), while others demonstrated a form of cautious, proportionate action despite uncertainty. This involved proceeding with initial management or referral while recognising their limits and seeking appropriate support (Q6).

Participants also valued the experiential knowledge that many patients brought, reframing care as a collaborative process (Q8). Drawing on patients' expertise helped mitigate uncertainty and supported a more collaborative approach to decision-making. Despite these challenges, HCPs described a continued sense of professional responsibility and motivation to act in patients' best interests, even in unfamiliar situations (Q9). However, managing uncertainty was not solely an individual task, but one embedded within the ongoing relationships that characterise primary care.

### *Theme 2: Sustaining Relationships – The Glue That Keeps it Together Q14*

Participants emphasised their role in maintaining responsibility for patients within primary care, with continuity and familiarity enabling them to recognise changes and support safe clinical decision-making (Q9, Q12). However, many expressed concern that patients could be lost to the system in the absence of recall mechanisms or structured follow-up (Q11). Reliance on patient-initiated follow-up was seen to disadvantage those with additional vulnerabilities, particularly individuals who were housebound or had needs that limited their ability to engage (Q10).

Relational continuity enabled HCPs to build familiarity and recognise change over time (Q12). However, this continuity was increasingly undermined by fragmentation across services and transitions between providers (Q13). These disruptions weakened therapeutic relationships and risked loss of contextual knowledge. Despite these pressures, participants demonstrated persistence and commitment, repeatedly returning to the importance of relationships as the glue that keeps it together through small but significant relational acts that kept patients visible within the system (Q14). These findings suggest that continuity is not simply organisational, but a relational process actively sustained through everyday practice.

### *Theme 3: Working Around the System - You Just try to Make the System Work/Bending the System Q15*

Beyond individual interactions, relational work was shaped and often constrained by wider system factors. At the organisational level, HCPs identified system barriers that constrained coordination and consistency. Many were unsure of referral routes or how to access specialist advice, resulting in variable approaches across practices (Q16).

Communication with secondary care was frequently described as inconsistent, delayed or incomplete (Q17). These gaps left HCPs uncertain about ongoing management and frustrated by the time required to chase missing information. When collaboration worked well, it transformed care, with timely and accessible communication from cardiology improving efficiency and confidence (Q18).

Systemic pressures such as increasing workload, limited consultation time and funding pressures further affected morale and capacity (Q19). Despite these challenges, participants reflected on how approaches to care have changed over time, particularly in how ACHD is understood as a lifelong condition (Q20). Participants offered practical solutions to strengthen confidence and consistency, including clearer referral pathways, concise cardiology summaries and targeted education (Q21). They described bending rigid processes or finding informal routes to specialist advice, adaptive strategies aimed at making the system work for patients (Q15).

## Discussion

This study highlights the often-unseen work undertaken by primary and community-based HCPs to support adults with ACHD beyond specialist services, including managing uncertainty, sustaining continuity and coordinating care across systems. Participants described balancing limited familiarity with ACHD against ongoing responsibility for recognising concerns, coordinating care and maintaining continuity within fragmented healthcare systems. The findings suggest that the difficulties experienced by HCPs were not simply the result of limited condition-specific knowledge. Rather, they reflected the demands of sustaining responsibility for patients within systems that were often difficult to navigate and poorly connected across organisational boundaries.

This tension was particularly evident when participants were required to coordinate and sustain care despite limited familiarity with ACHD. Consistent with previous research, ACHD was experienced as an infrequently encountered but clinically complex condition within generalist practice, characterised by limited education and infrequent exposure.[8,12] Uncertainty was therefore not simply a gap in knowledge, but an ongoing feature of practice. Participants described concerns about missing important clinical information, uncertainty regarding referral pathways and discomfort when working beyond familiar areas of expertise. These experiences resonate with descriptions of moral distress, in which clinicians are unable to act in accordance with what they believe to be the right course of action because of factors beyond their control.[16]

Although participants rarely articulated these experiences in explicitly ethical terms, their accounts reflected concern about whether they were able to provide the care patients needed, particularly when they could not access timely specialist advice, lacked clarity regarding ongoing management or worried that patients might become lost between services despite their efforts to maintain continuity of care. Nevertheless, participants continued to coordinate care, seek solutions and support patients over time, reflecting a form of moral agency expressed through efforts to act in accordance with professional and ethical values despite system constraints.[16] Participants demonstrated this through efforts to coordinate care, advocate for patients and maintain continuity across organisational boundaries. When communication and collaboration supported them, they described confidence and purpose. When relational continuity was disrupted by fragmentation across services and administrative barriers, HCPs described feeling constrained in their ability to act. The findings suggest that moral agency is not simply an individual characteristic but is supported through relationships, communication and organisational structures that enable HCPs to fulfil their responsibilities effectively.[17-19] While moral agency highlights how participants sought to act responsibly within existing constraints, their accounts also raised broader questions about where expertise, decision-making and support should sit across primary and specialist services.

Participants described recognising concerns, coordinating care and sustaining continuity while simultaneously relying on specialist expertise when required. Viewed through the lens of subsidiarity, these accounts highlight both the potential and the limitations of locating responsibility within primary care. Subsidiarity proposes that decisions should be made as close as possible to the patient, while higher levels of expertise provide support when needed.[20,21] While primary care professionals were often best placed to provide continuity, holistic support and coordination, they frequently described relying on informal routes, personal relationships and individual initiative to bridge gaps in care. These findings suggest that responsibility can be effectively located within primary care only when accompanied by timely access to specialist expertise, clear referral pathways and supportive relationships across organisational boundaries.

Continuity emerged as a key process through which HCPs sustained care despite limited ACHD familiarity and organisational constraints. Familiarity with patients and ongoing therapeutic relationships enabled recognition of change, coordination of care and maintenance of patients' visibility within complex healthcare systems. Consistent with previous evidence, continuity supported both patient engagement and clinicians' capacity to act.[22-24] However, participants described continuity as dependent on individual effort and informal workarounds, making it vulnerable to disruption.

The findings highlight the interdependence of generalist and specialist expertise in supporting adults with ACHD. Participants valued specialist knowledge but described the greatest benefits when communication was timely, accessible and

collaborative. Effective care appeared to depend not only on specialist expertise, but also on the relationships through which knowledge, responsibility and support were shared across services. These findings suggest that opportunities for communication, shared learning and reciprocal exchange between specialist and generalist practitioners may help strengthen coordination and continuity of care.[25,26] As increasing numbers of adults with ACHD receive care outside specialist centres, recognising the complementary contributions of both generalist and specialist practitioners will become increasingly important.

Viewed collectively, the findings suggest that the central challenge for primary and community-based HCPs is not simply acquiring specialist knowledge of ACHD but sustaining continuity and responsibility for patients within systems that are often fragmented and difficult to navigate, while keeping patients connected to appropriate care over time.

### *Implications for Practice*

Given growing recognition of ACHD as a lifelong condition associated with increasing multimorbidity and ongoing healthcare needs,[9,12] inclusion within established long-term condition frameworks, such as the Quality and Outcomes Framework, could be considered as one potential mechanism to clarify roles, strengthen continuity and better recognise the contribution of primary care to ongoing management. This would support shared accountability across specialist and generalist services rather than shifting responsibility between them. Education should extend beyond clinical knowledge to include reflective and relational approaches that build confidence and support clinicians in navigating uncertainty. System-level improvements should focus on strengthening communication, coordination and opportunities for shared learning. Practical priorities include accessible specialist advice, clear referral pathways, concise care summaries and mechanisms for collaboration between specialist and generalist services, reducing reliance on informal workarounds.[25,26] Participants' accounts suggest that when such structures are absent, continuity becomes dependent on individual relationships rather than established pathways, increasing the risk of fragmentation and loss to follow-up. For cardiovascular nurses, particularly those working in community, outreach or liaison roles, these findings highlight the importance of accessible specialist advice, clear communication pathways and shared care models to support generalist HCPs.

### *Strengths and Limitations*

This study provides novel insight into how primary and community-based HCPs support adults with ACHD, a group underrepresented in existing research. By focusing on generalist practitioners, it captures the realities of managing an infrequently encountered but clinically complex condition at the point of first contact and during ongoing care coordination. The qualitative interpretive design enabled in-depth exploration of how knowledge, relationships and organisational factors shape practice, while reflexive thematic analysis and team-based discussion supported analytic rigour.

Participants were recruited from a single region of England and experiences may differ in areas with alternative service configurations or access to specialist ACHD services. Many reported infrequent exposure to ACHD. However, this reflects routine practice in community settings and was central to the study's focus on generalist care. The study explored HCP perspectives only, and future research should consider how these experiences align with those of adults living with ACHD.

## Conclusion

Primary and community HCPs play a vital role in the lifelong care of adults with ACHD. Their accounts highlighted the often-unseen work involved in navigating uncertainty, sustaining responsibility and preventing patients from becoming lost within fragmented pathways of care. Strengthening this role requires more than condition-specific education alone. It depends on healthcare systems that support communication, collaboration and continuity across organisational boundaries, alongside timely access to specialist expertise. The principle of subsidiarity offers a useful framework for understanding how care can be delivered as close to patients as possible while maintaining appropriate specialist support.

As increasing numbers of adults with ACHD receive care beyond specialist centres, effective care will depend not only on clinical knowledge but also on the relationships, coordination and organisational support that enable continuity over time. Recognising and supporting this work may be essential to developing more integrated, sustainable and person-centred models of care for adults living with ACHD.

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## Ethical Considerations

Ethical approval was sought and obtained from Health and Care Research Wales (REC reference 22/PR/0370).

## Consent to Participate

All participants provided written informed consent.

## Consent for Publication

All authors have consented for publication.

## Author Contributions

**SE:** Conceptualisation, methodology, investigation, formal analysis, data curation, writing – original draft, writing – review and editing. **RL**: Methodology, formal analysis, supervision, writing –original draft, and review and editing. **IJ**: Methodology, supervision, writing – review and editing. **PM**: Methodology, supervision, writing – review and editing. All authors approved the final manuscript.


## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project was undertaken as part of a PhD supported by a VC scholarship funded by Liverpool John Moores University.


## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Data Availability Statement

Data is not available due to risk of identification of participants.

## Guarantor

Sarah Ellison.

## Supplemental Material

Supplemental material for this article is available online.

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