



UNPAID CARERS

**UNDERSTANDING THE CARER EXPERIENCE:
CHALLENGES AND INSIGHTS FROM
RACIALLY MINORITISED COMMUNITIES ON
NHS SERVICES AND HOSPITAL DISCHARGE.**

Contents

SUMMARY	3
METHODOLOGY	4
SUMMARY OF KEY FINDINGS	6
COMMON THEMES AND KEY ISSUES	8
YOUNG CARERS	12
RECOMMENDATIONS FOR IMPROVEMENT	14
CONCLUSION	17

SUMMARY

Inclusive North was commissioned by the Lancashire & South Cumbria Integrated Care Board (ICB) to gather intel from racially minoritised communities regarding their experiences with NHS services.

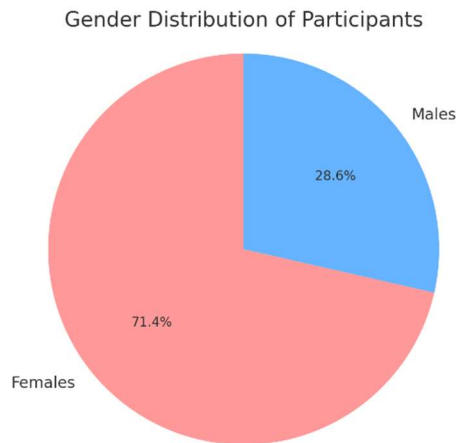
This work has highlighted the insights of the experience of racially minoritised unpaid carers and their experiences of navigating NHS health care, focusing on:

- GP Services
- Urgent Care
- Outpatient Appointments
- Inpatient Care
- Hospital Discharge Planning

The report aims to understand the entire process and difficulties faced by unpaid carers navigating various NHS services, with a particular emphasis on what constitutes a good hospital discharge from their perspective. It identifies common themes, key issues, and provides recommendations for improvement based on the carers' feedback.

METHODOLOGY

The focus group consisted of 42 unpaid carers who identify as being of from a racially minoritised group. Participants were asked to share their experiences related to navigating and utilising various NHS services. The data collected was analysed to identify recurring themes and issues that reflect the collective experiences of the groups.



30 Females

12 Males

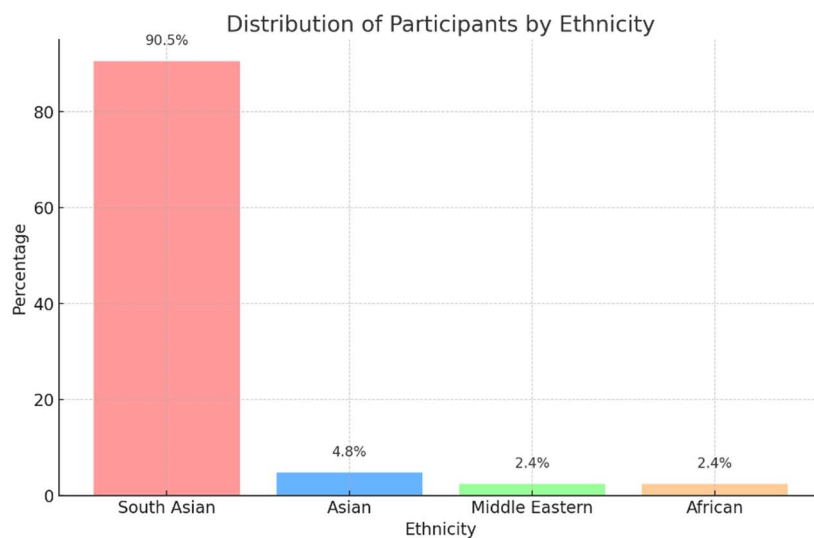
The bar graph below represents the ethnicity distribution of the participants:

South Asian: 38

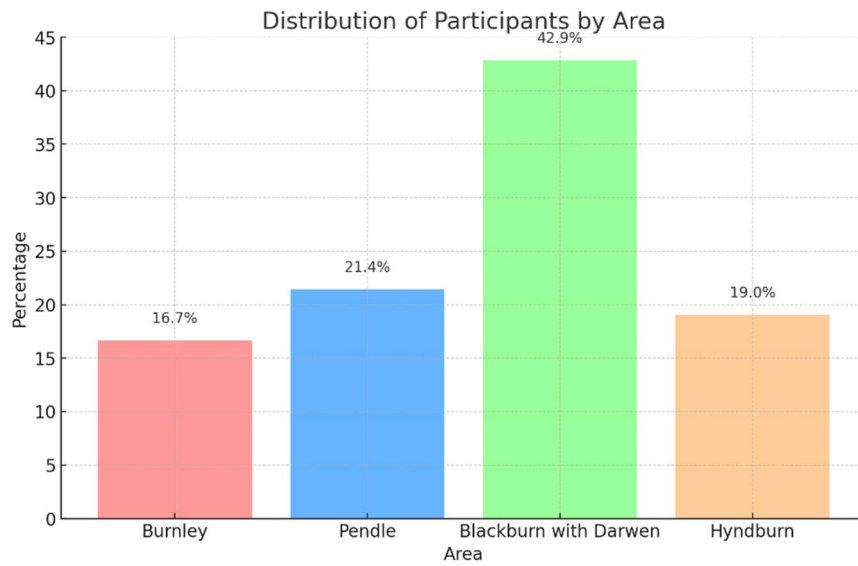
East Asian: 2

Middle Eastern: 1

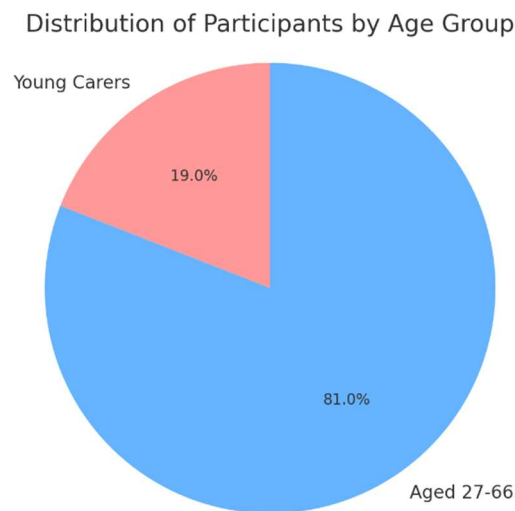
African: 1



Percentages of participants from each area: Burnley, Pendle, Blackburn with Darwen, and Hyndburn.



Pie chart representing the distribution of participants by age group, with 8 being young carers and 34 aged between 27 and 66.



SUMMARY OF KEY FINDINGS

These key findings underline the critical areas where improvements are needed to enhance the experiences of unpaid carers from racially minoritised communities in navigating and using NHS services.

GP Services:



Appointment Accessibility and Delays: Long waiting times for GP appointments and difficulties in booking systems were major concerns, with some carers waiting up to six months for an appointment.



Communication Barriers: Language barriers and poor communication from GPs were significant issues, leading to misunderstandings and inadequate care.



Staff Attitude and Stereotyping: Carers reported feeling dismissed and stereotyped by GP staff, with frequent use of locum doctors resulting in inconsistent care.

Urgent Care (111 and A&E Services)



Response Times and Efficiency: Carers experienced long waiting times for ambulances and in A&E departments, causing significant stress during emergencies.



Communication Issues: The 111 service was criticised for being too scripted, and carers often had to repeat information multiple times to different staff members.



Staffing Levels and Attitudes: Understaffed departments and unhelpful reception staff were common complaints, with carers feeling that urgent care services lacked efficiency and empathy.

Outpatient Appointments



Long Waiting Times: Delays in outpatient appointments and receiving test results were highlighted as major issues, adding to carers' anxiety.



Appointment Cancellations and Coordination: Frequent cancellations and poor coordination between NHS Trusts disrupted care and caused confusion.



Professional Attitudes and Communication: Healthcare professionals in outpatient settings often appeared rushed, making it difficult for carers to receive comprehensive information about treatment plans.

Inpatient Care



Hospitalisation Experience: Carers reported long waits for room admission, inadequate facilities, and patients being left on trolleys in corridors.



Staff Attitudes and Cultural Sensitivity: Rudeness and a lack of cultural sensitivity from hospital staff were significant concerns, with carers feeling their needs were not respected.



Communication and Support: Carers expressed the need for better communication and regular updates from hospital staff, as well as more support services tailored to their cultural and linguistic needs.

COMMON THEMES AND KEY ISSUES

GP Services

Appointment Accessibility and Delays

Difficulty in Booking Appointments: Carers reported significant challenges in securing GP appointments, with some experiencing delays of up to six months. This issue was exacerbated by complex and often ineffective booking systems, including online platforms and telephone lines that were frequently busy or unresponsive.

Home Visits: There was a notable difficulty in arranging home visits, which are crucial for patients who are immobile or severely ill. Carers highlighted the inflexibility of GP practices in accommodating home visit requests.

Communication Barriers

Language Barriers: Many carers faced language barriers that impeded effective communication with healthcare providers. The lack of interpreters and translated materials often led to misunderstandings and inadequate care.

Dismissive Attitudes: Carers felt that their concerns were frequently dismissed by GPs, who did not fully acknowledge the severity of the patients' conditions. This was particularly troubling when carers were trying to convey critical information about the patient's health.

Staff Attitude and Stereotyping

Perceived Stereotyping: Carers reported instances where they felt stereotyped based on their ethnicity, which affected the quality of care received. There were concerns that GPs made assumptions about their knowledge and capabilities, leading to a lack of respect and consideration.

Locum Doctors: The frequent use of locum doctors resulted in inconsistent care, as these temporary doctors were often unfamiliar with the patients' histories and specific needs. Carers expressed a preference for seeing regular GPs who had a comprehensive understanding of the patients' medical backgrounds.

Urgent Care (111 and A&E Services)

Response Times and Efficiency

Long Waiting Times for Ambulances: Carers reported excessively long waiting times for ambulances, sometimes up to five hours. This delay was particularly stressful during emergencies when immediate medical attention was required.

Extended A&E Waits: Upon arrival at A&E, carers and patients often faced prolonged waiting periods, sometimes extending to several hours before receiving care.

Communication Issues

Repetitive Information Requests: Carers frequently had to repeat critical information multiple times to different staff members, causing frustration and delays in care. This issue was particularly pronounced in the 111 service, which carers felt relied too heavily on scripted responses.

Lack of Personalised Care: The scripted nature of the 111 service did not accommodate individual patient needs, leading to a sense of impersonal and inadequate care. The lack of understanding means the carers would not reply on this service as their first point of contact.

Staffing Levels and Attitudes

Understaffed Departments: There was a clear need for more staff in urgent care settings to manage the high volume of patients effectively. Carers noted instances where staff appeared to be unoccupied while patients waited for care.

Reception Staff Conduct: Some carers experienced rudeness and unhelpfulness from reception staff, which added to the stress of seeking urgent care.

Outpatient Appointments

Waiting Times

Delayed Appointments: Carers highlighted the lengthy waiting times for outpatient appointments, which delayed critical medical assessments and treatments. This included long waits for MRI scans and other diagnostic tests.

Slow Test Results: Delays in receiving test results further exacerbated the anxiety and uncertainty faced by carers and patients.

Appointment Cancellations and coordination

Frequent Cancellations: Carers reported frequent cancellations of outpatient appointments, which disrupted care continuity and required rescheduling, often with significant delays.

Poor Coordination: There were issues with coordination between different NHS Trusts, leading to fragmented care and confusion regarding follow-up appointments and referrals.

Professional Attitudes and Communication

Rushed Consultations: Healthcare professionals in outpatient settings often appeared rushed, which made it difficult for carers to ask necessary questions and receive comprehensive answers.

Need for Clear Information: Carers emphasised the need for clearer and more detailed information about patients' conditions and treatment plans.

Inpatient Care

Hospitalisation Experience

Admission Delays: Carers reported long waits for patients to be admitted to a room, sometimes spending extended periods on trolleys in corridors.

Inadequate Facilities: Some carers had to sleep on chairs while accompanying patients, highlighting the need for better accommodation facilities for carers.

Staff attitudes and cultural sensitivity

Rudeness and Dismissiveness: There were significant concerns about the attitudes of nurses and other hospital staff, with reports of rudeness and a lack of empathy. Carers felt that their concerns were often not taken seriously.

Lack of Cultural Sensitivity: Carers from racially minoritised backgrounds noted a lack of cultural sensitivity and understanding from hospital staff. This included issues with language barriers and a lack of respect for cultural practices.

Communication and Support

Inadequate Updates: Carers expressed the need for better communication and regular updates from hospital staff regarding the patient's condition and treatment progress.

Support Services: There was a call for more support services tailored to the needs of global majority carers, including access to interpreters and culturally appropriate resources.

GP Services

The feedback on GP services was overwhelmingly negative, with consistent complaints about the difficulty in obtaining appointments and poor communication. The main issues highlighted include:

- **Appointment Accessibility:** Carers found it extremely hard to get appointments, often comparing the process to "pulling teeth".
- **Communication Barriers:** Language barriers were significant, leading to poor communication with staff.
- **Staff Attitude and Competence:** There were numerous comments about unapproachable and unhelpful staff, particularly receptionists.
- **Suggested Improvements:** Hiring more staff, especially for answering phones, providing more appointment slots, and enhancing the professional behaviour of receptionists were recommended.

Urgent Care

Experiences with urgent care services were mixed:

- **111 Services:** Generally seen as efficient, although some delays were noted in getting through automated messages and callbacks.
- **A&E Services:** Criticised for long wait times, often extending beyond 12 hours. The need for more doctors and responders was emphasised.
- **Communication and Interaction:** Effective communication with staff was a challenge due to limited time with doctors.

Outpatient Appointments

Outpatient services received mixed reviews:

- **Professionalism and Helpfulness:** Some carers found the staff professional and helpful, while others experienced rudeness and dismissiveness.
- **Wait Times:** Extended wait times for appointments and during visits were a common issue.
- **Continuity of Care:** Challenges in obtaining details from previous appointments and not seeing the same doctor consistently were noted.

Inpatient Care

Inpatient care experiences highlighted several areas of concern:

- **Language Barriers:** These were particularly problematic during night shifts when carers were not present to assist.
- **Staff Training and Attitude:** Rudeness and lack of attention from staff, especially at night, were recurrent issues.
- **Support for Carers:** Carers felt a need for more intimate rooms for end-of-life patients and the ability for family members to stay with patients to help with communication.

Self-Care

Self-care among carers was a significant concern:

- **Support Systems:** Carers often relied on family for support, but formal support from healthcare professionals was lacking.
- **Need for Additional Resources:** The suggestion of having opt-in carers and more frequent nurse visits to support self-care was common.

Understanding by Professionals

The focus group participants felt that healthcare professionals often lacked understanding of their role and needs:

- **Dismissal of Expertise:** Carers' knowledge about the cared-for person's condition was frequently overlooked.
- **Cultural Sensitivity:** A call for healthcare professionals to be more educated on ethnic backgrounds and languages to improve communication and care was evident.

Awareness of Carers' Needs

The general perception was that healthcare professionals were not adequately aware of or responsive to carers' needs:

- **Emotional and Physical Toll:** The impact of caring on the carers' well-being was often unrecognised, affecting their ability to provide care effectively.

RECOMMENDATIONS FOR IMPROVEMENT

Based on the feedback from the focus group, the following recommendations are proposed to improve the experiences of unpaid carers in the NHS:

Positive Aspects and Areas for Improvement

While there were some positive experiences, particularly regarding individual staff members, the overall sentiment was one of needing substantial improvement:

- **Supportive Services:** Instances where carers felt supported were rare, often limited by language barriers.
- **Improvement Suggestions:** Key recommendations included better training for healthcare staff on the role of carers, more accessible interpreter services, and enhanced communication and empathy from GP receptionists.

Enhance Appointment systems

Simplify and improve the efficiency of appointment booking systems for GP services and urgent care. This includes better access to online booking, more responsive telephone lines, and flexible options for home visits.

Improve Communication and Cultural Sensitivity

Train healthcare staff in effective communication techniques and cultural sensitivity. Ensure the availability of interpreters and translated materials to bridge language barriers and improve patient understanding.

Increase Staffing Levels

Address staffing shortages in urgent care and inpatient settings to reduce waiting times and improve patient care. Ensure that reception staff are trained to be courteous and helpful.

Ensure consistency of care

Promote continuity of care by minimising the use of locum doctors and ensuring patients see the same GP or specialist regularly. This is crucial for managing long-term and complex health conditions.

Provide Better Support for carers

Recognise the vital role of unpaid carers and provide them with the necessary support, including clear communication about treatment plans and access to resources when they are unwell.

Enhance coordination between services

Improve coordination between different NHS Trusts and services to streamline referrals and reduce delays in treatment. Establish clear communication channels to ensure seamless patient care across different healthcare providers.

These recommendations aim to address the key issues identified by the carers and improve the overall experience of navigating and using NHS services for both carers and the people they care for.

Hospital Discharge

The hospital discharge process faced criticism mainly due to delays:

- **Waiting for Medication and Paperwork:** Carers often waited hours for discharge medications and paperwork.
- **Suggested Improvements:** Recommendations included preparing medications and paperwork in advance and providing digital copies of discharge papers to reduce waiting times.

How can Carer experience inform quality of discharge alongside other measures?

Collaborating with the carer helps them understand the situation and plan ahead. This reduces the need for them to chase answers. Independent feedback from Carers allows services and providers to identify best practices and areas for improvement.

What can be done to make this happen?

- Maintain clear, open, and honest communication between Carers and professionals.
- Avoid assuming the Carer has medical training or is comfortable with complex care tasks. Open dialogue and training sessions can address this.

How can this learning be shared with staff groups?

Key stakeholders must commit to ensuring that the report and interviews inform the work of decision-makers. This information should be shared with health and care service staff to raise awareness of the identified challenges and necessary actions.

What is the best way to raise the profile of unpaid Carers?

- Carers' voices should be included at all levels of health and social care. Their input must be used meaningfully in decision-making, not just as a formality. Given that many people will experience caregiving at some point, it's important to discuss unpaid Carers in the workplace and all health and care settings.
- Understanding the role and legal protections for Carers should be integrated into impact assessments, policies, service delivery, and training.
- Addressing these issues through better training for healthcare professionals, improved appointment and discharge processes, and recognising the vital role of carers can significantly enhance the care experience for both patients and their carers.

CONCLUSION

The focus groups have demonstrated that each Carer is an individual, and understanding their specific needs is crucial for ensuring a smooth discharge process. Findings indicate that effective communication and collaboration with the Carer during the hospital stay are essential for a positive outcome. This includes setting clear expectations for the discharge timeline.

Another key aspect is having honest discussions about the required care and the Carer's ability to provide it. If the Carer cannot provide the necessary care, they should be guided to appropriate support resources.

To address these needs, it is essential to:

Ensure the Carer is well informed about:

- The patient's condition
- The care being provided
- The expected discharge date
- Prerequisites for discharge

Any necessary training or skills the Carer might need, and offering non-judgmental support if they cannot meet these needs.

Create trusted spaces for the Carer to discuss their capability to care for the patient and direct them to support when needed.

Approach each Carer as an individual, without assuming their ability or willingness to provide care.

Foster a culture that eliminates bias, or assumptions based on the Carer's or patient's age or culture.

The focus groups demonstrated that discharge works well when both the patient and Carer are involved and understand the process.

By addressing these issues through targeted improvements and ongoing support, the NHS can significantly enhance the healthcare experience for unpaid carers and the individuals they care for, ultimately leading to better health outcomes and a more compassionate and effective healthcare system.