Ethnically diverse people's experience of reablement and intermediate care services





Background

Why we did this engagement:

Very few people* from ethnically diverse backgrounds are accessing intermediate care and reablement and we want to understand the reasons for this.

What we did:

- Visited community groups.
- Spoke to people who had experience of needing additional support following discharge from hospital.
- Gathered feedback from staff who are involved in hospital discharge.

*For example, in 2023, 95% of people accessing intermediate care beds via Calderdale and Huddersfield NHS Foundation Trust were White British; just 5% of people from other ethnicities accessed this type of care.



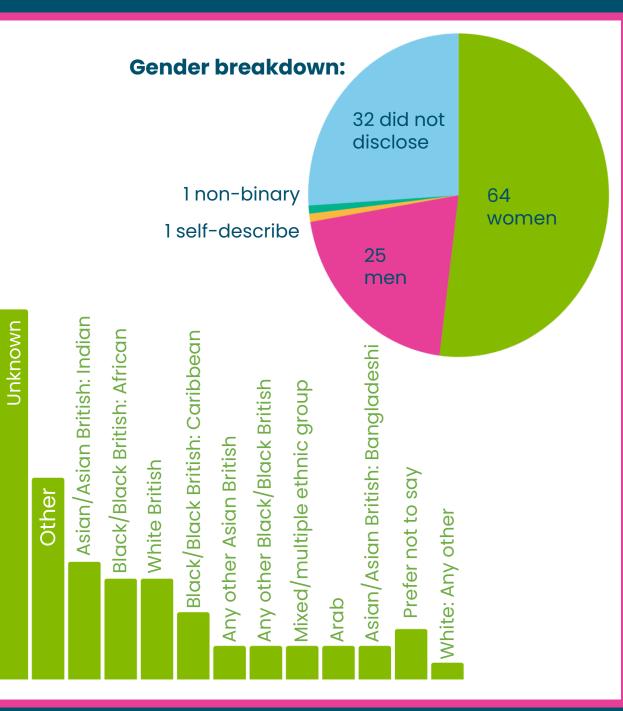
Demographic Overview

123 responses: 64 women, 25 men, 1 nonbinary, 1 prefer to self-describe and 32 did not disclose their gender.

Ethnicity breakdown of all who responded:

- 29% Asian/Asian British: Pakistani
- 22% unknown*
- 12% other
- 7% Asian/Asian British: Indian
- 6% Black/Black British: African
- 6% White British: English/Northern Irish/Scottish/Welsh
- 4% Black/Black British: Caribbean
- 2% any other Asian British background
- 2% any other Black/Black British background
- 2% Mixed/multiple ethnic groups: Black, Caribbean, and White
- 2% Arab
- 2% Asian/Asian British: Bangladeshi
- 3% Prefer not to say
- 1% White: any other background





Understanding of services

Many people from diverse communities did **not** know what reablement, intermediate care, and Age UK home from hospital services were.

- 44% did not know (54 individuals)
- 28% did not disclose (34 individuals)
- 28% said they do know (35 individuals)

The majority of those who did not know were Asian British Pakistani, Asian British Indian, and Black British African.



"Show what happens and how the family can also be involved in care alongside services so there is no stigma to my family for accepting help other than family members." Female, Asian/Asian British: Pakistani, 50-64, Kirklees "I don't think the language used is clear, I'm sure I could work it out but if you're not 100% you need communication to be easy, not something you have to think about... reablement isn't clear, maybe 'health rehabilitation' would be better but I can see there are negative aspects of that people may think of substance misuse, but reablement is a bit of a nothing word." Male, Black British, 50+, Calderdale

Likelihood of accepting support

We asked everyone if they would accept these services following discharge from hospital and the response was as follows:

- 33% Yes 41 individuals
- 20% No 25 individuals
- 19% Not sure 23 individuals

When we compared the data by ethnicity, 47% of people with any Black ethnic background said they would accept support, 28% of people with any Asian background told us they would accept such support after discharge.

"I would have liked the chance to go for intermediate care before going home as I would have liked physiotherapy to help with exercise after my operation. I would have liked someone to talk about what is on offer, explained medication, no one mentioned transport home so I had to arrange for someone to pick me up. I was asked if I needed an interpreter but this was not necessary."

Female, Asian/Asian British: Indian, Kirklees (no age disclosed)



"As a man, I would be ok with female carers, but not sure if I needed help with washing. Is there a choice of male carers?" Male, Black British, 50-64, Calderdale

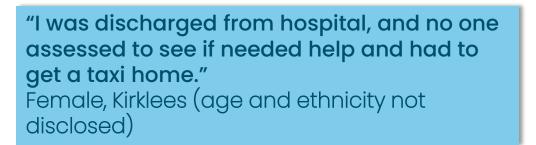
Barriers

We explored the reasons why people had not accepted reablement or intermediate care and the top themes were:

- 20% preferred care and support to be provided by friends or family
- 13% didn't know enough about these services
- 8% had concerns about having people in their home
- 8% said culturally, this was not something they would accept
- 7% faced stigma/concerns of care being in a care home
- 6% had financial concerns
- 5% faced stigma in accepting support
- 3% faced religious barriers
- 2% didn't think the services would be necessary
- Less than 1% cited a language barrier

Half of those who didn't know enough about the services were Asian British Pakistani.

"I would only take the help if I didn't have family and friends to support me but if that was the case I would want to know who was coming to care for me, would it be the same person everyday, would they be female etc." Female, Asian/Asian British: Pakistani, 50-64, Calderdale



Financial concerns were a barrier for some and may account for some declining support offered after discharge.

Those with 'more than enough money for basic necessities and a little to spare' were more likely to say 'yes' if they or someone they cared for needed support after discharge.

"I would want to know the cost, I had some support in the past many years ago and I couldn't afford it but had to pay it over a long period of time. I would be wary of accepting any support without someone writing down for me the cost or if it was free." Female, Arabic, 40+, Calderdale

"Having only recently arrived in this country language can be a barrier to get the information and being on a low income travelling to hospital is costly." Female, Kirklees (age and ethnicity not disclosed)

"I would accept help if I needed it, I would want some assurance that it was free and I wouldn't get a bill at the end. I wonder if I was desperate to get out of hospital I would agree to anything without realising the future implications like cost." Male, Black British, 50-64, Calderdale



Support needed following discharge from hospital

Half of the respondents (61 individuals) said they or a family member had been discharged from a hospital in the last 18 months.

Out of the 50% who were discharged (either themselves or a family member),

- 34% said reablement or intermediate care was not offered
- 21% said support was offered and accepted
- 21% said support was offered but declined
- 19% said further support was not needed
 Majority of those who declined the support and gave a reason were
 Asian/Asian British Pakistan.

Key themes:

- They felt they already had a network of support from family and friends
- Many deemed it wasn't culturally acceptable
- They had concerns about having people in their home



Quotes from people who were offered support but declined:

"I would have accepted the support but my family said they would do it instead. I live with my family and they help me with everything, think carers and family need to be involved. You need to bring awareness of services to the community and people. Translated (information) into other languages and family can take it away and read it. Someone to speak my language would be easier and a male carer." Male, Asian/Asian British: Pakistani, 80+, Kirklees

"I needed help with bathing and going to the toilet and I didn't want help from strangers for this. I felt more comfortable getting this help from my daughters." Female, Asian/Asian British: Pakistani, 50-64, Calderdale

"My late husband had declined the care in the home, he did not like to have people who were unfamiliar to him in the home. He hated being in hospital any longer than was absolutely necessary so would not considered intermediate care either. When he was in hospital he insisted I came in and washed him instead of the nurses. He strongly believed it was my responsibility as his wife to care for him and not others." Female, 65–79, Black Caribbean and White, Kirklees



Quotes from people who needed support but say they were not offered any:

"Being elderly generation when I got ill, I would have liked for someone to come in and help me with personal care and shopping/preparing meals etc. My family could not come in to help due to my illness and I had to be in isolation, and I live alone. At discharge I would have like to go to intermediate care, my family are all busy and work so this would have helped me, especially if someone could speak to me in my preferred language." Female, Kirklees (age and ethnicity not disclosed)

"Because she was walking they didn't offer any support, nothing was offered or discussed. I did ask for a bed but they refused because family member could walk I would have really liked help to bathe her and help her get dressed...."

Female, Kirklees, Asian/Asian British: Indian, 50-64

"I would have liked support such as intermediate care so would have accepted help as I don't have a support network of family living near me...It was very awkward for me and my wife when I left hospital. It was very difficult to get up when I had sat down so my wife had to help me who is also elderly"

Male, Kirklees, Asian/Asian British: Pakistani



How could services improve take-up of reablement and intermediate care after discharge

We asked people what services could do to make it more likely that they would accept support services after discharge. The common themes were:

- Nothing, they still prefer support from family instead
- More information about what happens, who would come for the care etc
- Information provided in different languages
- Reconsider the words used to describe the services
- Financial information made clearer i.e. whether there is a cost short or long term
- Family members involved in conversations about discharge support

"My father did not understand any of it had it not been for us as family translating to him. Very little was done to communicate with him directly. More information on who the carers would be and if they would be able to speak our language, Punjabi. I was more open to the idea but I was happy to listen to what my dad wanted. It would have made my life easier but I was not the priority." Male, Asian/Asian British: Pakistani, Kirklees (no age given) "I think carers and family need to be involved. You need to bring awareness of services to the community and people. Translated into other languages and family can take it away and read it. Someone to speak my language would be easier and a male carer." Male, Asian/Asian British: Pakistani, 80+, Kirklees



Gender key themes:

Every Asian man we spoke to said the main reason they would refuse reablement or intermediate care was because they prefer care and support to be provided by family and friends.

A greater number of women reported barriers or reasons to not accepting reablement or intermediate care. While their top reason was also preferring care to be provided by family or friends, women were more likely to report they didn't know enough about the services (15 women reported this reason compared to one man).

Women were also more likely to report that culturally, it was not something they would accept compared to men, pointing towards greater societal pressure on women from ethnically diverse communities to manage on their own or with support from family instead of accepting reablement and intermediate care.



"I think people in the black community feel we get a 'hands off' service sometimes, I'm not accusing anyone of race (sic), but I think there is some apprehension to touch us." Male, Black British, Calderdale (no age given)

"If I was in the position my husband was I would have been open to receiving care at home and I know my husband wouldn't be able to support me if it was the other way round and would need help." Female, 65-79, Black Caribbean and White, Kirklees

Carers key themes:

There may be a greater pressure on women to act as carers for family members, especially in ethnic minority communities. They may refuse reablement or intermediate care due to this cultural or generational pressure.

- 27 individuals considered themselves to be carers
- 67% (18 out of the 27) who considered themselves to be carers were women
- 37% (10 out of the 27 carers) were of Asian/Asian British Pakistani ethnicity When asked if the carer and the person you care for both shared the same opinion about the offer of reablement or intermediate care, the common theme was an expectation of the carer to provide the care for the family member and to reject the services offered.



"I do not know what intermediate care/reablement or Age UK Home from Hospital is... Culturally this is not something I would take up unless I really needed the help. I would also require female caretaker for myself and a male caretaker for my husband, someone who could speak my language and understand our culture and values and Asian cuisine."

Female, Age 25+, Asian, Kirklees

Responses from staff who support with hospital discharge

We had 25 staff responses from OT (1), physio (4), nurses (11), and 'other' (9) which include team leaders, coordinators, manager, specialist practitioners, and admin.

Almost all said they are very familiar with reablement and intermediate care services and very confident in referring ethnically diverse patients to these services. Only a quarter of staff told us they had received training specifically around referring patients to reablement or intermediate care.

Top 3 reasons why staff think ethnically diverse people don't accept these services:

- Prefer care and support to be provided by family
- Cultural barriers
- Lack of awareness about the services

Staff feel that the care provided by ethnically diverse families is often very good, both in hospital and when they return home.



There's a sense that cultural barriers exist, in that patients and families don't feel the service providers will meet their cultural needs. Also, that accepting this type of care would not be viewed favourable by family or the wider community.

"Culturally expected that family pick up the caring role. Concerns about care providers not being able to meet cultural needs." "Faith also plays a part particularly for Asian Pakistani communities. Certain rituals are important for things that involve personal care. Even when they are still an inpatient, for patients from these communities family tend to do all their personal care tasks and want very little involvement from the staff team."

Staff feel there is a lack of understanding about the type of care these services offer and worry about potential future costs. Staff also know that when negative experiences are widely shared within communities this leads to even fewer people accepting reablement and intermediate care.

"Families often ask questions about cost of care and although we explain it is free of charge for the first 6 weeks we have to make them aware care needed beyond that point is charged. They don't want to accept something that may cost them later. There is also a misunderstanding about what Reablement is as a service. Patients tell us of bad experiences they have heard of from other people in their communities where carers have not done their housework and cooking etc. There is a lack of understanding of the offer of help and what that looks like i.e. patients will be supported to become independent and not a cooking, cleaning and shopping service."

Information provided to patients and families

Staff offer interpreting services so that people understand what's on offer, and most feel their communication methods are effective. However, where staff rely on family members to translate, there can be concerns about whether accurate information is given to the patient to allow them to make an informed decision about their ongoing care.

Staff say there are no leaflets available to explain what the services offer, and no information in community languages.

"Staff often use family to translate when staff are not available. So although the final consent is always confirmed using an interpreter (not family) there is certainly a big influence by the family as they have communicated offer of support to them. I believe patients have very little say in their own care and in most cases family make the decisions." "I was once told by an interpreter that there is no similar word in Punjabi or Urdu to reablement and intermediate care so it's not straight forward to explain. We don't know what family are saying to the patient when we use them to translate so could be misinforming the patient." "Patients don't have a clue what reablement and intermediate care means. There are no leaflets about it either for patients to look into and consider."

"They don't know what it is to begin with. Have to do a lot of work (often with interpreters) to explain what it is."

Challenges for staff when referring ethnically diverse patients to reablement or intermediate care

Top 3 challenges

- Communication challenges
- Patient refusal
- Resistance from the patients' families

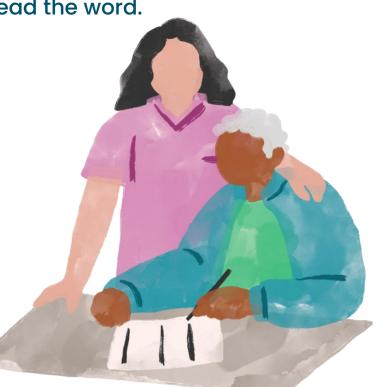


"The conversation around reablement and intermediate care usually happens once and if they decline it's not something that is re-visited unless there is a change in circumstances. I think there is too little awareness of what it is so it is often dismissed outright."

"People generally live in multi-generational households where it is rare that patients are left by themselves therefore families often prefer to support their relative due to this."

What staff think could be done to improve information about and access to intermediate care and reablement services for ethnically diverse people:

- Change the name of the services they are not easy for anyone to understand.
- Cultural awareness training for staff.
- Leaflets in community languages explaining what the services offer and how they can offer a personalised service to meet diverse needs. Include information about if and when someone would need to pay for care.
- Promotion of how the services can meet cultural and religious needs. Share success stories with local communities.
- Involve faith leaders/trusted community leaders so that they can help spread the word.
- More face-to-face interpreting services.



Healthwatch recommendations	Provider/commissioner response
Consider whether changing the name of 'reablement' and 'intermediate care' services would help patients, carers, and relatives to understand what they mean and what they offer.	
Provide written information about the services in community languages.	
Provide written information to say that reablement and intermediate care are free, and explain what happens one the services stops (e.g. financial assessments for ongoing care etc).	
Consider how the stigma associated with receiving care in a care home and in someone's home can be addressed.	
Improve access to interpreters so that there's less reliance on family/friends to interpret for a patient.	

Healthwatch recommendations	Provider/commissioner response
Share positive experiences and benefits about the care provided by reablement and intermediate care services. Show examples of how the services can provide personalised, culturally appropriate care. Share these experiences with people who are influential in ethnically diverse communities.	