ASSESSING THE IMPACT OF HEALTH INEQUALITIES ON ACCESSING LIFE AFTER STROKE SUPPORT SERVICES IN GREATER MANCHESTER

A collaborative projected funded by NHS England between the Stroke Association and the Greater Manchester Neurorehabilitation & Integrated Stroke Delivery Network

Published August 2022

EXECUTIVE SUMMARY

This pilot project was commissioned by the Greater Manchester Neurorehabilitation and Integrated Stroke Delivery Network (GMNISDN) and undertaken by the Stroke Association between November 2021 and June 2022.

The aims of the project were to learn about stroke survivors' personal experiences of accessing support for life after stroke in the north of Greater Manchester and to understand the potential impact of health inequalities.

Seventeen stroke survivors from Oldham, Rochdale, Bury, and North Manchester who had their stroke in 2021 plus three carers participated in "listening events" via video and phone calls. These sessions were transcribed and analysed thematically.

The preparatory stage of the project revealed systemic challenges that potentially hinder equal access to life after stroke services. There is a potential need for development work in:

- Accurate recording and sharing of ethnic background information
- Recording and sharing the stroke survivor's preferred language
- Stronger links between stroke support services and local organisations
- Knowledge and understanding by stroke professionals about ethnicity and culture

Participants, regardless of their ethnic background, felt that improvements in the following would help ensure better quality of life after stroke:

- Clear information in hospital about:
    - Their stroke (with space to ask questions)
    - Risks of another stroke and suggestions for changes to lifestyle etc
    - Next steps in the stroke pathway
- Prompt signposting to support services for life after stroke
- More focus on mental health status and emotional support

Those from non-white ethnic backgrounds felt there was a need for better access to culturally relevant information on stroke prevention, recognising stroke symptoms and acting on them, and life after stroke.

INTRODUCTION

The NHS defines a health inequality[1] as "*unfair and avoidable differences in health across the population, and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care that is available to them*". Whilst legislative measures such as the Equality Act (2010) and the Health and Social Care Act (2012) have been put in place to work towards reducing health equalities, it is crucial to understand first-hand experiences of individuals who are likely to face barriers in our health system.

In 2020/21, the North West of England recorded the second-highest prevalence of strokes registered in GP practices in the country, with 157,673 cases (appendix 1). In addition, 11 of the top 20 most socio-economically deprived areas are in the North West, including Oldham and Rochdale.

The project focused on Fairfield General Hospital's stroke service catchment area, which was selected in part because of its demographic diversity including ethnicity and deprivation. The aims were to understand the potential impact of health inequalities on accessing life after stroke support services by listening to individuals from Oldham, Rochdale, Bury, and North Manchester who had their stroke during 2021.

Life after stroke (LAS) describes the patient journey through personalised care and support following the acute stage in hospital and addresses the long-term needs of physical, social, and emotional aspects of recovery and well-being after a stroke. The National Stroke Service Model[2] states that LAS services should be accessible to all people affected by stroke from the very acute phase onwards.

The project was designed with the goal of understanding what barriers exist and what further research may be needed to support improvements in ensuring services are accessible for all stroke survivors and their families.

The report is ordered chronologically in terms of the progression of the project:

1. Stage One:

    A. Data collection for target population

    B. Insight gathering from health, social care, and third sector staff

    C. Learning from scoping

2. Stage Two: Listening Events
3. Stage Three: Analysis of Findings from the Listening Events
4. Learning, Recommendations, Further Development
5. Appendices

1. STAGE ONE
1.1. A: DATA COLLECTION FOR TARGET POPULATION

Stage one focused on two areas: 1) gathering data to understand the demographics of the population in question and 2) organising discussions with stroke professionals to obtain their insight. Data was extracted from the Sentinel Stroke National Audit Programme (SSNAP)[3] with support from the GMNISDN data lead and the data team at the Stroke Association. This provided insights into the demographics of individuals who had a stroke in 2021, and highlighted trends that further informed the listening phase of the project.

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[1]www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/
[2]www.england.nhs.uk/ourwork/clinical-policy/stroke/national-stroke-service-model/
[3]www.strokeaudit.org/

Office of National Statistics (ONS) data (2019 estimates) show 84% of people in England identify as White British, 8% as Asian or Asian British, 4% as Black, African, Caribbean, or Black British, 2% as mixed or multiple ethnic groups and 2% as other[4].

In contrast, the boroughs in this study generally have a higher proportion of residents from ethnic minority communities[567]. For instance, Asians represent 18% of the population in Oldham, 15% in Rochdale, and 17% in Manchester. In this context, when looking at the ethnicity of stroke admissions recorded by Fairfield General Hospital using the SSNAP tool (appendix 2), there is an over representation of patients reported as White British compared to what would be expected based on ONS data. Given that people of South Asian, Black African, and Caribbean heritage are also at higher risk of having a stroke, they are potentially under-represented in hospital's SSNAP data.

The age distribution within the populations of these four boroughs are similar to national data, with approximately 60% of the population aged between of 16 and 64 years and ~15% over 65 years[8]. Similarly, the ratio of the two sexes in the boroughs similarly reflected national proportions; 49% female: 51% male.

1.2. B: INSIGHT GATHERING FROM HEALTH, SOCIAL CARE, AND THIRD SECTOR STAFF

Information gathering included in-depth discussions with local stroke clinical leads as well as a range of organisations across the network, both stroke specific and more generalist, to highlight topics that would inform the listening phase of the project. Many sources contributed including: Stroke Association service teams (Oldham, Rochdale and North Manchester); Chief Executive at Speakeasy (Bury), Directorate Support Manager at Fairfield General Hospital; Network Facilitator at the GMNISDN; Clinical Lead at the Brain and Spinal Injury Centre (Salford); Chief Executive at Disabled Living, and the stroke team at Fairfield General Hospital.

A key thread that emerged was that professionals highlighted ethnicity and language as a key potential barrier to accessing LAS services in Greater Manchester. It was therefore important to ensure the project's participants included individuals not accessing LAS support and also from different ethnic backgrounds.

1.3. C: LEARNING FROM SCOPING

Besides highlighting areas that the listening events needed to focus on, the preparatory stage of the project revealed systemic challenges that potentially hinder equal access to support services. The scoping showed that there may be a need for development work in:

- Accurate recording and sharing of ethnic background information
- Recording and sharing the stroke survivor's preferred language
- Stronger links between support services and local organisations
- Understanding and knowledge of stroke professionals about ethnicity and culture

1.3.1. Accurate Recording and Sharing of Ethnic Background Information

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[4]www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/datasets/populationestimatesbyethnicgroupen glandandwales
[5]www.oldham.gov.uk
[6]www.visitnorthwest.com/population
[7]www.manchester.gov.uk/downloads/download/4220/public_intelligence_population_publications
[8]www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/populationandh ouseholdestimatesenglandandwales/census2021

Currently, eighteen categories are used on the SSNAP tool to record stroke patient's ethnicity (appendix 3). These categories do not always distinguish between nationality and ethnicity, and do not include religion. For example, 'British' and 'Indian' are nationalities, not ethnic groups. In addition, the categories are quite ambiguous; for instance, if an individual of British nationality has dual Scottish and Chinese heritage, they would have to choose between being 'White and Asian' and 'British'. Therefore, ethnicity may not be being accurately recorded on SSNAP and may lead to an over-representation of patients recorded as being from a White background.

By definition, the term 'ethnicity' is vague. It can be used to refer to any social group bound together by commonalities of race, language, nationality, or culture. When this information is collected in the health sector, it is concerned only with what physiologically distinguishes people i.e. race. The ethnicity data collected on SSNAP would be more useful if the options aligned with nomenclature in the Government census where there are five major groups, each with an 'any other' option so people can describe their ethnicity. We have fed this observation to the national SSNAP team as an outcome of this project.

At present, information on ethnic background is not always shared when referrals are made by stroke teams. This means that when a key worker such as staff at the Stroke Association make contact with the patient to offer LAS services, they often do not have many demographic details. This results in professionals having to ask for the patient's ethnicity over the phone, which could be perceived as intrusive. However, without information on a stroke survivors ethnic background, the patient may not be referred to support to meet their needs potentially impacting their ability and willingness to engage with services that could aid their recovery.

1.4. Recording and Sharing the Stroke Survivor's Preferred Language

Information gathering revealed that stroke survivors' preferred language is currently not being captured or shared by professionals and was felt by some professionals and support staff to be a potential barrier to supporting someone following a stroke. Whilst recording ethnicity contributes data on SSNAP, it doesn't provide much practical information to help organisations offer appropriate services after the point of discharge. For example, knowing that an individual is Asian or even more specifically Indian, doesn't provide any indication of what language they might speak - the Indian Constitution recognizes 22 official languages. Individuals may also speak more than one language, with some more common than others which can impact finding an interpreter.

Individuals might also speak a particular language, but this does not automatically mean that they can read/write in that language. Therefore, providing information leaflets in different languages may not always ensure inclusivity and enhance access to LAS support.

Whilst some LAS services offer multiple languages, there is a risk of stroke survivors being excluded if first contact is not made in their preferred language, or if information is not shared in a language they can read. If service providers are aware of the preferred language, they might be better able to offer support in that language and develop connections to be able to signpost the patient to local organisations and groups that can help. Therefore, best practice may be for professionals to record (and share) the patient's preferred language for communication, both in written and spoken forms.

1.5. Stronger Links between Support Services and Local Organisations

Work is ongoing to develop a national LAS service model within the National Stroke Service Model framework that focusses on the improvements needed for long-term personalised care and support. It is therefore important that the links between key workers in stroke support teams and local support organisations are strengthened for better, more inclusive referrals. In addition, stronger links built with culturally diverse local organisations may help ensure that stroke survivors from an ethnic minority understands the referrals being made and what that means for their recovery.

1.6. Conversations and knowledge in the health system about ethnicity and culture

Some professionals reflected that they did not feel equipped in terms of culturally understanding the diverse population they support. They felt that their lack of knowledge may hinder understanding of the needs and support that could be provided, especially if the patient came from an ethnic minority community. This implies a need for more structured education and knowledge building within the stroke care system about ethnicities and cultures that are represented in local patient populations.

2. STAGE TWO: LISTENING EVENTS

The next stage of the project conducted between March-May 2022 were listening events. To advertise the opportunity, a flyer/consent form was put together by the Stroke Association and circulated through multiple routes. The focus was on stroke survivors currently not accessing any LAS services.

A variety of local organisations were contacted to help share information with their members and users about the events (appendix 4). Whilst this did help bring in a handful of participants, we learnt that organisations cannot just be contacted when participants for a project are required. Long-term collaboration should be fostered to work towards developing support networks for stroke survivors who do not access stroke-specific support services.

Whilst the focus was on stroke survivors, seventeen stroke patients and three carers participated. 65% of stroke survivors identified as White British, with the remainder drawn from South Asian and Black communities. 35% were under 60 years old, 26% were 60-69 years, 29% were 70-79 years and the rest were over 80 years. 53% of the stroke survivors were females, and 47% were males.

The listening events were conducted via Zoom videoconferencing and individual phone calls. There were a total of two Zoom events with three stroke survivors in each, with the remaining participants preferring one-on-one phone calls. Each call started with a brief description of the project and what the participant was there for, followed by recording the participant's details (name, age, ethnic background, when they had their stroke) and obtaining consent to record. The Zoom calls also included setting some ground rules for respectful listening and participation. Each individual session lasted between 10-30 minutes, depending on how much detail the stroke survivor provided.

A series of prompts were used to ask about various aspects of the stroke survivor's journey (appendix 5). Whilst these were used to structure the conversation, most discussion flowed organically. Many participants focused their narratives around the acute stage in hospital and inpatient rehabilitation, which perhaps reflected their experience of not receiving significant LAS support.

The events ended by thanking the participant and letting them know how to submit further information they might want to share in the near future. Each conversation was transcribed and then thematically coded.

3. STAGE THREE: ANALYSIS OF FINDINGS FROM THE LISTENING EVENTS

This section provides a detailed, stroke survivor-centric description of the information gathered through listening events. Some transcripts are from the carer's perspective. The learning has been grouped into the following themes:

- Information provision
- Mental health support
- Clear signposting and referrals

3.1. Information Provision

Both stroke survivors and carers felt their expectations had not always been met in terms of being provided with information that enabled them to understand what had happened (with respect to the stroke), and what that meant for the individual's health going forward. This appeared to cause fear, anxiety, and general distrust of the health system regardless of the stroke survivor's ethnic background and also impacted access to ongoing support:

I didn't feel safe, what if I had another attack, what if I had another stroke?

Why did this happen to me? What if anything in my lifestyle aided and assisted it. If anything. Knowing and understanding this would surely help others to avoid. Intervention to stop must be better than dealing with the event. Nothing in my treatment has focussed on this. Only the dealing with the issue after it has occurred.

The same lack of information was also observed with respect to what the stroke pathway looked like including therapy, reviews, and recommendations to avoid having another stroke. Participants said they had many unanswered questions when they left the hospital, particularly about further steps such as referrals:

How long does she have this feeding peg for? Will she ever be able to eat? How long does this carry on? There's so many questions, but nobody there to answer them.

There's no real information about what the reviews are. I had no real information that I would be called (after 4 weeks), other than just this phone call, a brief discussion. Nothing else was said about any further review.

I was told I will probably have another stroke. But I have no information about how to avoid it, or how to spot the symptoms. I would like to know more about that.

The pandemic and subsequent lockdowns in 2021 resulted in greater social isolation than normal, making the experience of having a stroke and receiving adequate support particularly challenging:

Every ounce of help he got was virtual. It was either over the phone, or a conversation with me to then relay to me dad. He had nothing at the door...(saying) we can do this, we can do that. We had to fight tooth and nail for every single bit of help that he's had.

As a consequence, the carers in particular seemed to feel that the burden to seek accurate information fell to them:

My dad was lucky that I had information- where I could get information from, and where I could get assistance from. It all kind of fell on me to do. Because my husband had been previously terminally ill and I lost him years ago, I knew how to become a registered carer for somebody, what doors that would open.

I didn't know anything, to be honest. The lack of support...I didn't have any idea. I had to learn as I went along. Get in touch with people myself. The support, personally, is not there. I feel once we're out of hospital, you gotta fend for yourself.

It was noticeable that when it came to recognising stroke symptoms, being aware of required action, and seeking information/support through services, the majority of participants who were unable to do so were from minority ethnic backgrounds.

Despite the lack of information, most stroke survivors felt their transition from hospital to home was satisfactory, particularly with respect to physical support needed during recovery:

I was surprised at the amount of equipment they had fitted into my house. Chair, seats for the toilets, a walking frame, a four pronged stick, and then they got sort of something that fits over the bath, I can sit in the bath and have a shower. And then two perching chairs, one in the kitchen and one in the bathroom. And a rail attached to the bed so I can heave myself up to get out of the bed. It was all provided.

Fairfield, and the doctors...they've been absolutely brilliant. They've suggested that I use this or I use that. Everything, grab rails, toilet rails...everything was brought and installed within 5 days. They were absolutely amazing.

3.2. Mental Health Support

An area where many participants felt they had not been supported at all was mental health. They felt that their experience did not include any explanation of the impact of stroke on mental health, and the resulting need for professional help during recovery:

If I fell from atop the stairs, people would know I need help because I had broken my leg. But they don't know I'm ill in my head. They can't see it.

You can't tell anybody what it feels like...who hasn't had a stroke. Suddenly you're plunged into this world that was created for you. And I slipped through the net. My family was concerned, I was quite poorly in my head... which I think could have been prevented with some communication.

3.3. Clear Signposting and Referrals

Overall, participants felt they would have had a much better experience if there was more communication within the healthcare system. This included the various professionals in the stroke pathway being aware of the patient's case history and better signposting to support services:

I'm seeing different people about different things, and they are all connected- but I am not sure they are all speaking to each other? Despite it being on the notes...

The let-down was the transition from the emergency department to ongoing care, for me. We've got no choice. While my care at the emergency team was brilliant, the signposting...it's like we're done now, but the next signposting hasn't been built. In a way I also feel like it let them down, they were working hard in one area, but...it came back to bite them.

4. LEARNING, RECOMMENDATIONS, AND FURTHER DEVELOPMENT
4.1. Learning

The project highlighted a number of challenges around culture and language that potentially hinder equitable access to LAS support by people from minority ethnic backgrounds:

- Inaccurate recording and sharing of patient's ethnicity and preferred language
- Insufficient level of understanding and knowledge of stroke professionals regarding ethnicity and culture
- Poor links between LAS services and local culturally based organisations

The impact of these challenges are emphasised by the patient experiences reported in the listening events. Whilst they indicated feeling satisfied with their experience within hospital services, they highlighted also that improvements in access to information, clear signposting and referrals, and mental health support may ensure a better quality of LAS support.

4.2. Recommendations

The project has resulted in some clear next steps that could be taken forwards locally:

- Improvements in the accuracy of ethnic background information on SSNAP would aid the identification and assessment of health inequalities. There would be clear benefit in a change in the national categories used currently and more focus on precise reporting by the local stroke teams inputting data.

- Adequate capturing and sharing of patient information (e.g. preferred language) by healthcare professionals would aid development, provision of, and access to culturally appropriate information and support to ensure access to LAS support.

- Development of better cultural awareness knowledge of local populations by stroke professionals would help them provide patients with relevant information and support for LAS.

4.3. Further Development

There are regional and national stroke improvement work streams currently in development that provide opportunities to help improve patient experiences and outcomes. The information gathered in this pilot may help shape this work:

- An NHS England led project to scope the current provision of the new national LAS service model and its implementation is in development. The learnings of this pilot may be used to further develop accessible and relevant longer-term support, such as relationship development and collaboration between those involved in LAS support and communities from minority ethnic backgrounds.

- GMNISDN has a work stream underway to improve access to emotional wellbeing and psychological support after stroke so that stroke patients across Greater Manchester can access equitable support.

- A number of the challenges highlighted in this project could be addressed through the planned implementation of a personalised patient stroke record provided on discharge by Greater Manchester stroke units. This will ensure every stroke survivor leaves hospital with a booklet containing accessible information tailored to them to help understand what has happened and what to expect next such as physical

symptoms, emotional needs, rehabilitation, and LAS recovery and feels better able to engage with services they have been referred into. A "My Stroke" document was developed in 2017 but implementation has been difficult and is currently being revisited with every stroke unit.

- Cardiovascular disease prevention is a GMNISDN priority, with a project to target providing culturally relevant information in local Muslim communities already in progress.

Finally, the following points should be considered when planning future development work in health inequalities:

1. Relationships between local organisations need to be created with long-term, sustainable goals as opposed to collaborating for limited projects. This will enable the participant pool to be more representative of the population being studied.
2. Involving a diverse range of stroke survivors in the steering group would ensure they are at the heart of developments
3. This project was conducted by someone who was multilingual and could speak to all participants in their mother tongue- this was a huge benefit in terms of communication
4. Acknowledging the cultural variations within minority ethnic communities, and tailoring projects around each one in question rather than a generic one-size-fits-all approach (with respect to research methodology) could result in more nuanced findings.
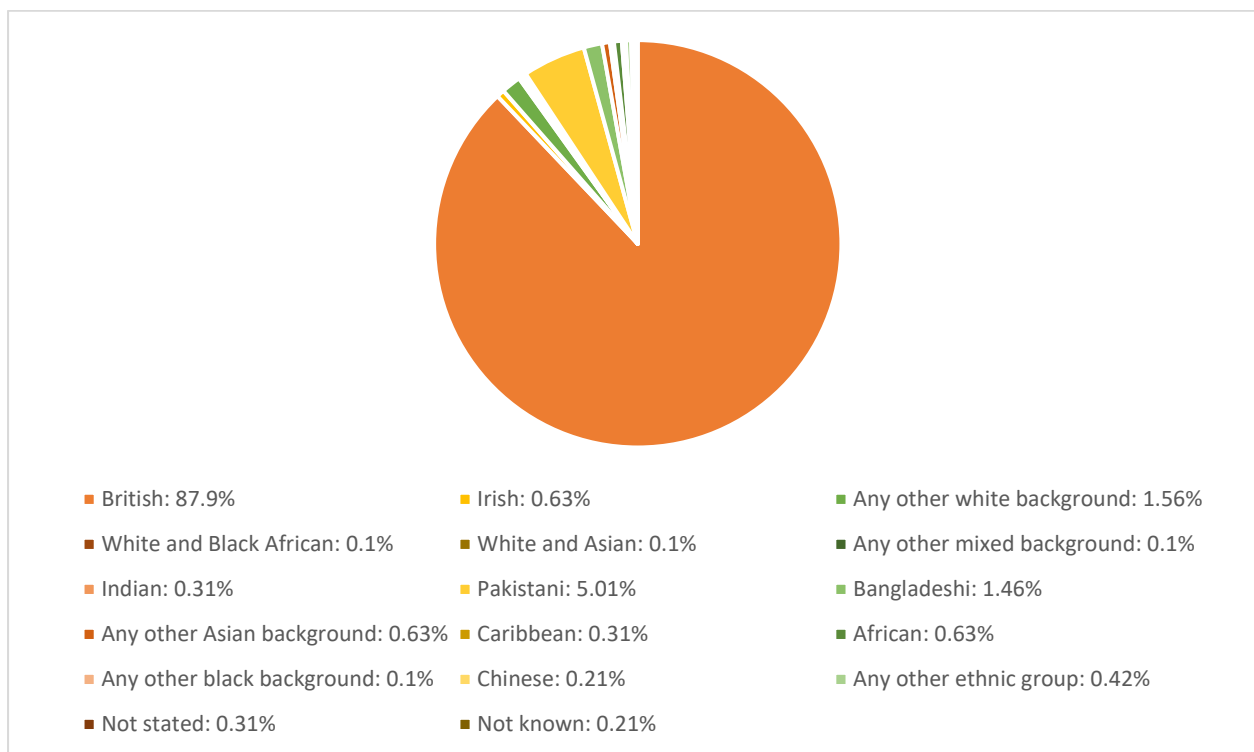
7. APPENDICES

Appendix 1. Prevalence of stroke cases in England (2020/21)

Stroke: QOF prevalence (all ages) 2020/21   Proportion - %

Area	Recent Trend	Count	Value		95% Lower CI	95% Upper CI
England	↑	1,093,593	1.8		1.8	1.8
South East region	↑	164,700	1.8*		1.8	1.8
North West region	↑	157,673	2.0*		2.0	2.0
East of England region	↑	118,713	1.8*		1.8	1.8
West Midlands region	↑	118,658	1.9*		1.9	1.9
Yorkshire and the Humber region	↑	117,186	2.0*		2.0	2.0
South West region	↑	112,718	2.2*		2.2	2.2
London region	↑	111,390	1.1*		1.1	1.1
East Midlands region	↑	84,522	2.0*		2.0	2.0
North East region	↑	63,904	2.3*		2.3	2.3

Appendix 2. Ethnicity of stroke patients registered at Fairfield General Hospital (2020/21)

- British: 87.9%
- Irish: 0.63%
- Any other white background: 1.56%
- White and Black African: 0.1%
- White and Asian: 0.1%
- Any other mixed background: 0.1%
- Indian: 0.31%
- Pakistani: 5.01%
- Bangladeshi: 1.46%
- Any other Asian background: 0.63%
- Caribbean: 0.31%
- African: 0.63%
- Any other black background: 0.1%
- Chinese: 0.21%
- Any other ethnic group: 0.42%
- Not stated: 0.31%
- Not known: 0.21%

Appendix 3. Ethnic categories used for the 2011 Census of England and Wales

White
- English, Welsh, Scottish, Northern Irish or British
- Irish
- Gypsy or Irish Traveller
- Any other White background

Mixed or Multiple ethnic groups
- White and Black Caribbean
- White and Black African
- White and Asian

- Any other Mixed or Multiple ethnic background

Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

Black, African, Caribbean or Black British
- African
- Caribbean
- Any other Black, African or Caribbean background

Other ethnic group
- Arab
- Any other ethnic group

Appendix 4. Organisations that collaborated in recruiting participants

Speakeasy	Caribbean and African Health Network
British Muslim Heritage Centre	Asylum Matters
Kashmiri Youth Project	Europia
Bangladesh Association and Community Project	Yaran Northwest
Deeplish Community Centre	Bury VCFA
Pakistani Resource Centre	Healthwatch Bury
Wai Yin	Adab
Action Together	Age UK
Henshaws Society for the Blind	Beacon Service

Appendix 5. Prompts used for Listening Events

1. What happened during discharge?
   - How was it explained to you or your loved ones?
   - Were you given any printed information to take home?
   - Were you referred to any support services?)
2. How did you feel when you were back home?
   - How were you supported?
   - Did you feel involved in your care decisions?
3. What did you need after coming back home?
   - What would ideal support have looked like?
   - How did you find out what support was available?
4. What support did you find useful?
   - Are you accessing any support services now?
   - Did you access any social care?
   - How have you been supported within your community?
5. What could be done better?
   - What made you feel let down?
   - What support would be useful going forward?
   - What improvements would you recommend for the health system?