

# Incorporating Perspectives from Lived Experience into PhD Research Design on Deafness and Hearing Loss

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## Introduction

In the UK, 1.2m people have severe hearing impairment which means they cannot hear most conversational speech (RNID, 2023). This has implications for their general health and wellbeing.

People who are D/deaf or hard of hearing (HoH) also experience discrimination and barriers to accessing healthcare leading to poorer outcomes (Alexander et al, 2012). Prior to the pandemic, D/deaf people had consistently worse experiences and outcomes in the management and prevention of ill-health (Abou-Abdallah and Lamyman, 2021). Following over a decade of austerity policies in the UK and the compounding factors of the Covid-19 pandemic, health inequalities have widened and the impact on the health outcomes for people with disabilities has been more severe than for the non-disabled population (Marmot et al, 2020).

Having established the broad area for the research, I felt it was inappropriate to decide the research questions and specific direction for the study without input from people with lived experience. The Disability Rights motto “nothing about us without us” (Charlton, 1998) should be held in mind when undertaking any research around impairment and disability.

## Methods

Participatory research involves the people affected by the focus of the research in the process of designing and conducting it (Wallerstein et al, 2017). Traditional approaches to research tended to be controlled entirely by academics, from the initial conception through to completion with people’s lived experience excluded apart from when they were invited to provide data (Wallerstein et al, 2017). This process was exploitative and research participants, particularly those from marginalised groups, often lost trust in academic researchers (Warwick-Booth et al, 2021).

This research began with a series of *Community Conversations* with a range of stakeholders (see table below) who were D/deaf/Hard of Hearing or who had experience in supporting people in these populations. These informal conversations took place in groups and one-to-one, online and in person.

The overarching question was: *what should research in the area of D/deaf/HoH people and health focus on?*

## Community Conversations

|  |                                               |
|--|-----------------------------------------------|
|  | Community and Voluntary Organisations         |
|  | Lived Experience: Deaf Community (BSL)        |
|  | Lived Experience: deaf and HoH People         |
|  | NHS Staff who support D/deaf and HoH patients |
|  | Academic Research Network                     |
|  | Online forum                                  |

## Findings

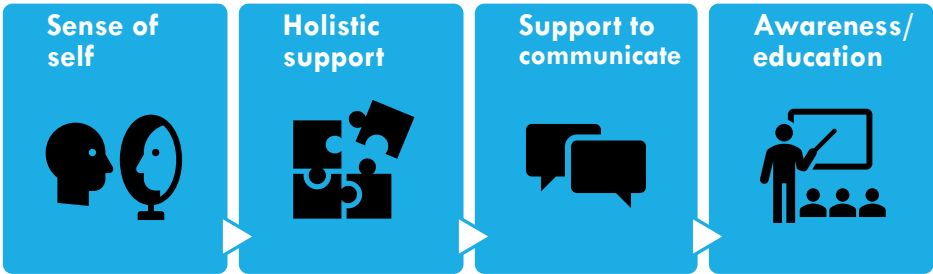
NVivo was used to analyse detailed notes taken from the conversations with Deaf (BSL users), deaf, and hard of hearing (HoH) people, staff from voluntary/community organisations, NHS staff (e.g. audiologists, doctors, patient experience team), academics in this area. Comments from a diverse range of people on a closed Facebook page for Deaf/deaf/HoH people were also included. This analysis was summarised as a list of research priorities that I then categorised into four themes:

**Sense of self:** how identity and belonging are affected by terminology, stigma, isolation and independence /interdependence.

**Holistic support:** how to move beyond the medical model, reducing ‘deafload’, what support is needed – psychosocial, peer, joined up?

**Meeting communication needs in health:** more than BSL, technology – help and hinderance, what is good practice, deaf awareness training, impact on accessing healthcare.

**Awareness and education:** about deafness beyond BSL, how to communicate with deaf/HoH people, education of healthcare professionals, sharing information on managing hearing loss and general health.



## Developing the Research Questions

The themes from the Community Conversations were mapped against the academic literature to identify research gaps. The literature reports extensive research on age-related hearing loss, hearing impairment in children, and the experiences of Deaf people who use BSL, but there appeared to be a lack of accounts from people who lost hearing as working age adults and their support needs, particularly in the current context where austerity policies have had a significant impact.

The Community Conversations and the review of the literature informed the initial research questions for the study:

1. How does hearing loss affect the sense of self and community people feel, and how does this affect health?
2. What does good holistic support look like for people who lose hearing as an adult?
3. What role can peer support play in improving health outcomes?
4. How can NHS services meet the communication needs of patients who are deaf/HoH?
5. How can education and awareness of how to support people who are deaf/HoH be increased and lead to empowerment over their health?

## Next Steps

The Community Conversations informed the research questions and the target population for research participants. A semi-structured interview schedule was then designed based on the research questions. In phase one of the study, 15 participants have taken part in interviews.

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