How to increase inclusivity of stroke survivors with aphasia in quality improvement projects?

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1. Introduction and Background

As part of stroke national guidelines, stroke services should actively engage with stroke survivors and families to collaborate in the development and strategic improvements of services. [1,2,3,4]

Hearing the patient and carer voice is integral to working in a patient-centred way. Working co-productively will ensure that the decisions about service for patients reflect what is truly needed.[5]

Maidstone and Tunbridge Wells NHS Trust (MTW) currently receive stroke survivor feedback from the national stroke survey commissioned by the Stroke Association, Friends and Family Test and outreaching to stroke survivor volunteer organisations.

Aphasia is an acquired disorder of language impacting significantly on communication and participation in daily life and represents 30% of stroke survivors.[6] They require specialist support from speech and language therapists (SLT) to enable the needs, voice and insights to be shared.

Stroke survivors with aphasia and other acquired disorders of communication, are often excluded or missed within methodologies of patient engagement, service improvement and research, with only 28.6% of studies with intended inclusion.[6] MTW decided to set up a stroke advisory group with the additional SLT support to enable stroke survivors with aphasia to participate and be an integral part of discussions.

Aim	To enable a stroke survivor voice to influence the development of MTW stroke services.
Objectives	☐ To contribute to development of NIHR stroke research studies ☐ To increase inclusivity of those with aphasia to participate in group ☐ To provide expert input on local quality improvement projects ☐ To provide expert feedback on their experience of the MTW stroke pathway ☐ To design an accessible survey to capture stroke survivor feedback for those who will use MTW stroke services in the future ☐ To be involved in co-producing specific local projects to help with supporting stroke survivors using MTW strokes services e.g. aphasia friendly leaflets and clinics letter ☐ To provide updates to stroke survivors on progress and changes on MTW stroke services

2. Methodology and Methods

The collaborative approach of public and patient engagement methodology was used throughout this project.
Scoping sessions were completed with local stroke survivor voluntary groups to understand the additional support required and generate ideas on the purpose of the stroke advisory group. In collaboration with stroke survivors and their family it was felt that the stroke advisory group should focus upon quality improvement projects, potential investigator-led research trials, input on NIHR portfolio trials uptake and co-produce local projects. With a particular focus on increasing engagement of those with aphasia, as this cohort of patients can get excluded from the research and patient engagement process, due to their post stroke complexities.[7]

Group set up: quarterly meeting for 2-3 hours to enable time for communication barriers and needs to be support appropriately. Due to financial constraints, it was held in a hospital facility on Hermitage Court, where there was ample free parking and disabled facilities.
Team members; 2 SLTs, 1 Clinical lead; 1 stroke research team 1 patient research ambassador; 3; stroke survivors and family members
Data collection methods and analysis; consent was gained from stroke survivors and family members to take notes of salient points within the discussions and photographs of work produced. Aphasia friendly minutes, agendas and action plan was collated and thematic analysis process was initiated using the first session notes.[8] There will be an iterative process in subsequent meetings, until data saturation is completed.
Additional resources and support required which included photos of the staff members, stroke unit and aphasia friendly consent forms and information leaflets.

3. Results and Findings

The additional support from SLTs and resources they provided, helped to adapt the conversation to people's needs including; the use of pictures, adapted written documentation, education with other facilitators and family member, to enable an inclusive environment and the time for those with aphasia to express their thoughts and opinions around agenda points, service improvements and research projects. The results were shared at local governance meetings.

Key codes from meeting discussions:

Code	Meaning
Emotions of event	The variety of different feelings and emotions felt by patients and family leading up and during stroke event within MTW services
Autonomy and independence	Stroke survivors wanting to complete tasks by themselves to create a feeling of control and autonomy of their lives whilst within hospital.
staff taking on additional responsibilities	When team member are taking on additional elements within their daily routine which go beyond their normal skillset e.g. psychology support
Small steps	Monitoring small steps helps both patient, relative and staff to see the improvements made on the journey. This is a key and special part of long-term motivation and management post stroke currently being missed.
Acceptance of change	The support required to come to terms about next steps and chapter within their lives.
Care and compassion	The underpinning feeling that drives culture within the service
Speed and personalisation of care	The services provided where timely and adapted to patients' individual circumstances
Continuity of care	Having familiar staff support with rehabilitation tasks or spending time with them on the ward helped build up the therapeutic relationship of Trust which provided confidence to trial activities they may not have deemed challenging.
Language	The words used in conversation or written information that creates a connection and understanding about the current situation to the patient/ family member reading them and the impact that can have on their future journey.
Missing rehab	The elements of rehabilitation that was felt should have been focus upon more during the admission to aid recovery.

4. Learning and conclusions

The MTW stroke advisory group provided learning around the additional support and resources required to enable those with aphasia to be included in patient engagement and research design. It allowed us to start to improve our understanding of local level need for aphasic patients accessing our services and consider improvements that need to be made to increase equity. The impact of this work is currently at a micro local level, however there is scope to further expand the remit of this group as we run more sessions to support investigator-led research projects and co-design local services and staff education programmes, as this was an important theme from discussions.

Sharing the learning from this project is important to help improve accessibility and inclusivity of aphasic patients for other stroke services to ensure their insights shape service developments and research designs.

5. Overall Contributions and Future Plans

Within stroke research and service delivery, increasing involvement of those with aphasia is vital to improve applicability of research findings and ensuring services and evidence base practice is inclusive to all stroke needs. The stroke advisory group demonstrated the importance of having specialist SLT support, aphasia friendly documentation and adequate time to allow those with communication difficulties time to express their expert opinion and feedback. It provided a depth of information which can be missed using standard patient feedback methods and has provided a baseline group to take future local service developments and research for coproduction and feedback.

Future plans:
We are aware that the initial group is small and next steps is to increase the number of stroke survivors attending, increase our advertisement and further the inclusivity of the group attending.
Further analysis of meeting notes to provide more information to move codes into categories and themes.
Completion of projects and action points by group will benefit future stroke survivors. Sharing our learning and skills required to involve those with aphasia is local QIP and research will help facilitate more opportunities for those with language issues post stroke sharing their opinions and working collaboratively with local services, to better meet their needs.

6. References

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