Patient and Public Voice in Stroke Service Redesign: A case study

Key words: Patient and Public Involvement (PPI); Bristol, North Somerset and South Gloucestershire (BNSSG); Health Integration Team (HIT); Clinical Commissioning Group (CCG); Sustainability and Transformation Partnership (STP), Bristol Health Partners Academic Health Sciences Centre (AHSC)

Introduction

This case study is about the patient and public co-design of stroke care across Bristol, North Somerset and South Gloucestershire (BNSSG). It explores the contribution of public and patient partners to the BNSSG reconfigured stroke care pathway over a five-year period between 2017 and 2022 and celebrates the role of patient and public involvement (PPI)[1] in health and care service development. In describing this work, we will demonstrate the effectiveness of this model of PPI for other areas of health and care service development.

The case study looks at the factors that both facilitated and challenged the impact of PPI on the reconfigured care pathway.

Background

> *'Stroke is both a sudden and devastating life event and a long-term condition. It's the fourth biggest killer in the UK, and a leading cause of disability. Over recent years, there have been significant advances in proven, highly effective methods of stroke treatment and care. The growing evidence of the benefits of centralised models of "hyper acute" stroke care forms the basis of a new draft National Stroke Service Model. Better immediate care limits the extent of*

[1] Within this context PPI is defined as both involvement such as co-production and engagement to influence decision making.

> *brain damage after stroke and early intensive rehabilitation reduces disability and preserves post stroke independence. There is an expectation that all areas in England will work towards achieving this care model to meet the national commitments, to improve outcomes for people that have a stroke, which were made in the NHS Long Term Plan.'* (BNSSG Stroke Programme Clinical Design Group, Programme Evaluation Plan (v4.0), September 2021**)**

Stroke care in the BNSSG area was identified by the BNSSG 'Healthier Together' Sustainability and Transformation Partnership (STP) Senior Leadership Group as a priority in May 2016.[2] It was recognised there were, and historically had been, significant regional variations in the provision of care, outcomes, and access to specialised services. As a result, there was compelling evidence for change in local stroke services. This change was required to cope with an expected increase in demand for stroke care, but also for services to make the most effective use of available specialist stroke workforce.

The STP Senior Leadership Group mandated a full stroke pathway review in line with the Sustainability and Transformation Plan for BNSSG. A Stroke Reconfiguration Programme Board (also referred to as the Programme Board) was established to lead the review of the entire care pathway. The subsequent merger of NHS Bristol, North Somerset and South Gloucestershire Clinical Commissioning Groups to create a BNSSG CCG in 2018 provided a platform on which stroke service development could be taken forward

The Bristol Health Partners Stroke Health Integration Team (HIT)[3] set up in 2017 proved to be instrumental in establishing public and patient co-design of the pathway and driving accountability. The Stroke HIT aimed to achieve a patient-focused, evidence-based, collaborative, and innovative approach to improving prevention and

[2] BNSSG Stroke Services Reconfiguration Programme Pre-Consultation Business Case FINAL Version: 3.3 24/05/2021

[3] Bristol Health Partners is a strategic collaboration between the city region's universities, major health and care providers and commissioners, covering Bristol, North Somerset and South Gloucestershire. These 11 organisations are part of Bristol Health Partners voluntarily, and we are funded by contributions from the partners. The Bristol Health Partners HIT model was established in 2012 to bring together healthcare professionals, managers, patients and members of the public, commissioners, local government, voluntary and community organisations and researchers to address pressing public health challenges and improve health outcomes.

management of stroke in BNSSG. The HIT membership meant that it was well placed to support the review of the stroke care pathway. Also, during its development phase the HIT had built links with stroke survivors and carers and had been supporting their involvement in the emerging STP Stroke Pathway Review.

Once the HIT was fully operational in 2019, the HIT Lead Director, Dr Phil Clatworthy (Consultant Stroke Neurologist, North Bristol NHS Trust) and Co-directors Dr Phil Simons (BNSSG CCG Clinical Lead for Stroke), and Sara Blackmore (Director for Public Health, South Gloucestershire Council) decided to offer two Peer Co-directorships to individuals with direct experience of stroke care to lead on public and patient involvement in its work. The recruitment was supported by People in Health West of England[4], and following an interview process two Peer Co-directors were appointed – Chris Priestman and Stephen Hill. In 2019, Claire Angell who was then Chair of the Bristol After Stroke Service User Group, was invited to join the HIT and in 2020 she formed and went on to lead the Stroke HIT Service User Group. Claire had previously, in 2016, been interviewed by the HIT to be involved in the stroke pathway review and was a member of the Programme Board.

This case study tells the story of how the HIT, through its Peer Co-directors, Service User Group, and other public contributors embedded people with lived experience in the Programme Board and in the co-design of stroke services in BNSSG (NB the term 'HIT public contributors' will be used to describe these roles collectively throughout the case study). The actions and innovative ways of working described are evidenced in various documents and informed by conversations with the Peer Co-Directors, the HIT Service User Group Lead and other key players in the stroke reconfiguration, within both the HIT and BNSSG CCG.

What did we do?

[4] People in Health West of England (PHWE) is a partnership initiative that aims to promote a strong and public voice within health and social care research and help to improve services provided by NHS and social care. Its public involvement team support Bristol Health Partners and other members of the PHWE partnership with PPI.

Prior to the present stroke reconfiguration, many of those initially involved in the development of the HIT were integral to the STP Stroke Pathway Review. Commenting on this afterwards, the HIT Director felt that the perseverance of public contributors involved with the Pathway Review served to have a motivational effect on others when the Review was paused during the merger of the three CCGs. In 2019 when work fully recommenced with a new Stroke Reconfiguration Programme Board (replacing the STP Stroke Pathway Review), the then fully operational HIT was formally engaged by the STP to support PPI for the pathway reconfiguration. The HIT went on to play a key role in supporting the programme board and the resulting transformation of stroke services in BNSSG.

The critical value of the Stroke HIT public contributors in shaping proposed service changes and helping to ensure the reconfiguration reflected the needs of people who have had a stroke as well as their families and carers, was acknowledged in a letter to Bristol Health Partners in February 2021 from the BNSSG Stroke Reconfiguration Programme Lead and Programme Board Chair. They identified the following key contributions made by HIT public contributors and others from the Stroke HIT up to that point in the process.

- **Stroke Programme Board membership and governance**
  The HIT public contributors attended monthly meetings of the Programme Board and .. 'also presented at key governance reviews to the Healthier Together Partnership Board and CCG Governing Body, helping to ensure the programme gained the support and backing to continue to progress' (Dunn & Burton, 2021). This level of attendance continued over a period of two years, initially in person and then remotely when the meetings were held online because of the Covid-19 pandemic.

- **Sub-group membership**
  The HIT public contributors were also invited to sit on sub-groups set up by the Programme Board to look at specific aspects of the reconfiguration. For instance, the Service User Group Lead attended meetings of the Integrated Community Stroke Service Group and Early Discharge Group. In these

meetings, she offered a service user perspective to every aspect of the clinical services proposed, including service specifications, discharge criteria, early discharge planning and future services planned, i.e., six-month reviews and patient personal outcome measures. She was also a member of the Clinical Design Group and attended clinical design workshops. When writing to Bristol Health Partners in 2021, the Stroke Reconfiguration Programme Lead and Programme Board Chair remarked that public contributor involvement in the clinical design workshops provided '..challenge and guidance to our clinicians as they develop future pathways for Stroke patients, both in and out of hospital' (Dunn & Burton, 2021)

- **Pre-consultation Business Case (PCBC) development, review, and appraisal**

  The Stroke HIT was integral to the process of preparing the Pre-Consultation Business Case (PCBC) for the reconfigured pathway and developing option cost models for consultation. The Programme Board felt it was important that the PCBC received scrutiny from those with lived experience to reflect what is important to stroke patients. Formal mechanisms were put in place to gather feedback from the HIT public contributors on each chapter of the business case. This involved feedback on options appraisals and attending a two-day options appraisal workshop to determine what should be presented in the PCBC. The HIT Director referred to tense moments for the acute health trusts involved when considering business case options, such as closure of one of the acute stroke units in BNSSG as part of the preferred option for hyper-acute and acute services, however the public contributor voice 'cut through this very well' and was key to getting the decisions made. In outlining the involvement of HIT PPI in the PCBC, the Programme Board lead commented that public contributors '..have been integral to the development of key chapters, reviewing and revising full content and supporting its progression through internal and external governance.' (Dunn & Burton, 2021)

  One of the HIT Peer Co-directors felt his comments on the PCBC as it developed were taken seriously. For instance, from his experience of being in meetings with African-Caribbean community organisations he was able to

highlight the risk relationship of sickle cell disease with stroke and suggest that this be included in the PCBC. Though not immediately picked up, sickle cell diagnosis and treatment were subsequently considered by the Programme Board as they were aware of other views supporting this link.

- **Service user co-design**

  The HIT Service User Group is made up of co-opted members of the existing Bristol After Stroke Service User Group. The HIT wished to reach a broader audience of stroke survivors for involvement in the pathway redesign and in particular for the public consultation on this. This had the positive effect of putting the HIT on a formal footing with the Programme Board. The HIT Service User Group Lead supported the development and running of this group, helping to build on earlier public engagement. The group worked in partnership with the CCG and senior clinicians to ensure the reconfiguration of services would reflect the needs of people who have stroke as well as their families and carers. It was directly involved in commenting on the PCBC and was involved with sub-groups such as the Early Discharge Service group, also working with the CCG Insights & Engagement Team to formulate the public consultation documents. The involvement of the HIT Service User group and other public contributors in meetings was enhanced by the introduction of remote working. Not only did it remove the challenge of physically getting to meetings faced by some public contributors, but also made it easier for people across a wider geographical area to participate, e.g. across the whole of BNSSG. Also, for one public contributor attending meetings online was helpful as the effects of her stroke are not as visible.

- **Development of 'Life after Stroke' services**

  In November 2020, the HIT public contributors became involved in running a group set up by the Quality Improvement and Engagement Manager for the Programme Board to work with Bristol After Stroke and the Stroke Association around integrating voluntary sector services in the reconfigured stroke pathway. There had been past resistance to the two organisations working together. However, through their existing relationships with these

organisations, the HIT public contributors worked to facilitate collaboration and support a collective offer to run an integrated community stroke service within the pathway, and then continued to guide planning for integration of this offer with the wider system.

- **Consultation planning and communications**
  During the development of the PCBC, HIT public contributors and the HIT Service User Group helped shape initial planning for the public consultation on the reconfigured pathway, and also supported the roll-out of communications to staff. The Programme Board felt it was important to have input from people living with the experience of stroke as CCG Insights & Engagement team lacked this. The CCG Insights and Engagement Officer working on the consultation acknowledged the unique and extensive benefits from the high level of public contributor involvement in this process, and the help of the HIT Service User Group in providing knowledge and insights around the consultation. She worked with separate groups to co-design materials for the Public Consultation, and to gather feedback on the approach to consultation, looking at how to ensure a consultation which was accessible and equitable.

  A good example of how the HIT was able to inform the consultation process and strengthen the perspective of those with lived experience, was through facilitating the involvement of people with aphasia. One of the HIT Peer Directors, set up a HIT aphasia group led by people who have aphasia. The group then organised a meeting with members of the public with aphasia to identify how best the CCG could ensure people with communication difficulties post stroke could take part in the Public Consultation. The meeting was held in collaboration with Healthier Together, the CCG and Speech and Language Therapists from University Hospitals Bristol & Weston NHS Foundation Trust and North Bristol NHS Trust. The meeting came up with recommendations for the CCG consultation planning and communications group and created accessible resources with help from speech therapists and communications staff from Healthier Together. Learning from this pilot project

was then applied to the public consultation documents on the stroke pathway reconfiguration.

HIT public contributors were also very much involved in the public consultation on the reconfigured pathway. As well as having a voice on the Programme Board the HIT public contributors were active in promoting the public consultation in 2021. Whilst the CCG used their strong links with physicians running services to reach and recruit potential public contributors within service user groups to widen PPI involvement in the public consultation, they were also keen for the HIT public contributors to share their experiences with the public. HIT public contributors attended online events and spoke with people in Bristol After Stroke cafes and recent stroke survivors on Next Steps courses to share their experiences on emergency treatment, ongoing hospital, rehabilitation, and integrated stroke services.

In launching the Public Consultation, the Clinical Chair of the CCG, Dr Jon Hayes, publicly thanked the public contributors for their involvement in the reconfiguration:

> '*This is the culmination of a huge amount of work, and I'd like to thank everyone involved to date - particularly the stroke survivors who have contributed their time so generously in shaping the proposals.'* (Bristol Health Partners Newsletter, Public consultation on changes to hospital stroke services announced, 8 June 2021)

The involvement of the HIT public contributors has been advantageous to the pathway reconfiguration process by strengthening the degree of public involvement expected by various official bodies such as the CCG Governing Body, NHS England, and Joint Health Overview and Scrutiny Committee (JHOSC) in respective local authorities. For instance, the HIT Service User Group enabled the involvement of more people with lived experience and their families and carers. The CCG Insights & Engagement team found the Group really useful in terms of networking and reaching a wider population in the public consultation. Also, they could signpost anyone approaching the CCG to the Service User Group.

What were the challenges?

The challenge of involving a sufficiently wide range of perspectives is common to PPI. During the stroke pathway reconfiguration, the CCG were aware of the challenge of reaching specific groups. For example, involving the voice of the carer and the perspective of people who have very recently had a stroke. The HIT public contributors did not aim to represent specific groups or interests (although they were concerned about the involvement of under-represented groups and in some cases could facilitate access to certain groups, such as those with aphasia). However, they were aware of the common ethical challenges and power issues around PPI. As one public contributor commented it takes courage '..to raise your hand in a meeting to disagree with a stroke consultant who may have saved lives' and a certain level of confidence to know when it's necessary to bring a different perspective. A further challenge is to make PPI meaningful. There were times at the start of their involvement when the Peer Co-directors were concerned about tokenism towards public involvement within the early Stroke Pathway Review structures. Avoiding tokenism has been discussed extensively in the literature on public involvement.

Both the HIT public contributors and the CCG talked of the need to factor in extra time when working with people affected by stroke because of physical or cognitive difficulties. For example, needing more time to prepare for meetings. One of the public contributors mentioned the challenge of reading documents when eyesight has been affected by stroke and commenting on papers when typing ability or memory has been affected. While the CCG acknowledged the need for extra time, and adjusted accordingly, it found this challenging when timescales were short, e.g., as the public consultation launch date approached.

Prior to the shift to remote working and online meetings in March 2020 (made necessary by the Covid-19 pandemic), travelling to meetings was also an issue for some public contributors. The Programme Board meetings were held in locations that were not very disability friendly, e.g., for parking, location of toilets, ability to get a disability scooter into a lift. The CCG acknowledged these issues.

Working within complex structures, the consistent use of acronyms, and the length of time before seeing any change were other challenges faced by public contributors. The stroke pathway review and reconfiguration has been a long process. For some HIT public contributors there were times when this process has felt directionless (e.g., during the CCG merger and restructuring) and public contributors needed staying power and resilience to remain involved. Some found the lack of continuity in membership of the Programme Board and sub-groups over the five years was disruptive and posed a challenge to public contributor impact. In particular, it presented an issue for the transfer of information. For example, one of HIT Peer Co-directors felt that some of the recommendations from the public meeting led by the HIT Aphasia Group to the PCBC Communications Group in 2019 were lost by the time a new Communications sub-group was set up in 2021 by the CCG Insights & Engagement Team. Whilst the HIT public contributors were very much involved in commenting on documentation for the public consultation, this protracted interval and then a short timescale to prepare for the launch meant that it was too late to take on some of the HIT Aphasia Group original recommendations or to consult with them on the eventual design of documents for the consultation. When the CCG Insights and Engagement Team reflected on the consultation process and gathered feedback on this from the HIT public contributors, a key learning was that the lead in time and the feedback (i.e., feeding back on what had or had not been included in the documentation), could have been improved for this part of the process.

Differing payment processes for reimbursing public contributors for their time was identified as a further challenge. It became evident that different organisations involved in the reconfiguration had differing hourly rates for PPI and processes for payment, which led to confusion over whom to submit expenses. This took time to resolve. The need for a standardised, and an easy-to-complete expenses claim form and process was recognised by the CCG.

What has changed as a result?

As discussed already, this model of patient and public involvement enabled HIT public contributors to influence various stages of the stroke pathway reconfiguration.

Their critical value in shaping proposed service changes was acknowledged by the BNSSG CCG in March 2021. They influenced the wording used in the options appraisal, and related communications. They contributed directly to the selection of a single hyperacute stroke unit for BNSSG. They were instrumental in building good relationships across different providers of services in the reconfigured pathway. Through existing contact with local voluntary sector organisations they helped to achieve a significantly enhanced offer for the Integrated Community Stroke Service. They were heavily responsible for ensuring that people with aphasia were able to contribute to the public consultation and the HIT Service User Group played a huge part in making sure documents were accessible to those who have had strokes, and to more diverse communities. For instance, on their advice the Programme Board were encouraged during the public consultation to hold face-to-face meetings in places accessible to these communities.

The following examples help to illustrate the beneficial outcomes and impacts of public contributor involvement in a little more detail.

The PCBC

Public contributor comments on the many iterations of the PCBC were taken seriously and can be viewed as a particularly powerful impact of public contributor involvement in the stroke programme. For instance, the Quality Improvement and Engagement Manager for the Programme Board reported that this provided learning on what is important to stroke patients such as the role of carers, the rehabilitation provider, and the importance of the rehabilitation journey. Their comments also led to discussion over issues which may not have been considered strictly within the remit of stroke services. For example, the inclusion of the risk relationship with stroke in the diagnosis and treatment of sickle cell disease. The Stroke HIT has now taken sickle cell on board as a focus for public education. The public contributors also argued for capacity for subarachnoid haemorrhage to be included in the PCBC. They realised this was not being considered and wanted to ensure that patients with this uncommon type of stroke would have access to the rehabilitation part of the reconfigured pathway. Subarachnoid haemorrhage is typically treated within neurological services and is not included in stroke national audit data, but it is included in stroke rehabilitation guidelines, therefore patients with subarachnoid

haemorrhage ought not to be excluded from the benefits of the stroke reconfiguration. Modelling numbers for the new pathway have since been changed to accommodate these patients.

The integrated community stroke service

Through their lived experiences of stroke, the public contributors have helped to identify specific problems and inequities in the care pathway and have helped to find solutions to these. A good example of this has been the strengthening of rehabilitation and support services within the pathway. The public contributors were key players in negotiations with local voluntary sector stroke care organisations to develop an enhanced bid to run key worker support services integrated with community rehabilitation services in the community. Through existing relationships, the public contributors were instrumental in bringing together organisations where there had previously been tensions (e.g., competing for funding) to work collaboratively to run community stroke services across BNSSG. They also worked on the integration of social care into the pathway, and element which is ongoing.

The reconfigured pathway now includes an integrated stroke service that will provide community rehabilitation and support to improve access for all patient groups and across BNSSG. Traditionally, following treatment in hospital, stroke patients would be offered five weeks of rehabilitation through 'early supported discharge' services. Patients not treated in hospital were unable to access these services and many patients had no access to these services at all. The newly commissioned Integrated Community Stroke Service (ICSS) will provide community-based rehabilitation for a much longer period if necessary, according to need. As part of the ICSS, the 'Life After Stroke' service will provide support and will include a six-month post-stroke review for everyone who wants one. As one public contributor commented - stroke recovery is not just about targets, all stroke survivors have different needs and there should be manoeuvrability in the transition between different stages of pathway.

The Public Consultation

Public contributors also had an impact on the public consultation process. They offered advice and expertise on how to ensure a consultation which was accessible

for those who have had a stroke and gave feedback on the plans for consultation activity. They pushed for the process to include different formats and languages to ensure it was more inclusive. For instance, CCG discussions with the HIT Aphasia Group led to the production of additional accessible versions of the consultation document, such as easy read and an animation. This ensured that people with aphasia could take part in the consultation. In addition, Healthier Together and the CCG were able to use public contributor stories at presentations and events about the reconfiguration. They were filmed and the Insights & Engagement Team reported the videos seemed impactful. The public contributor voice was prominent in media coverage of the consultation, which was almost exclusively positive. The strength of the involvement of stroke survivors in the process was reflected by their independent participation in media interviews, not solicited by the CCG. They were given considerable airtime on local radio and TV at the beginning and in the final stages of the consultation. It was clear that broadcasters wanted to talk to stroke survivors along with clinicians and a very long interview on Radio Bristol really caught public attention. As well as using the public contributor case study videos at events, public contributors also attended events and spoke about their experiences directly. This was very powerful in bringing stories to life and highlighting both the impact that a stroke can have on people's lives, and the impacts that the proposed changes could bring about. It also emphasised the involvement of lived experience representation in the programme.

When the results of the public consultation were announced, it was noted that the consultation had been unusually successful in accessing the views of different groups of society. The CCG Insights & Engagement team delivered a session in January 2022 to reflect on what worked well with this involvement and to note learning for other CCG public engagement activities.

Other outcomes and impacts of the public contributor involvement in the reconfiguration are evident in the personal stories of the Peer Co-directors and HIT Service Group Lead. Most significantly, they told of the impact on them personally of regaining confidence after the traumatic experience of stroke and feeling empowered by the opportunity to inform change by telling their stories.

Lessons learned

The Stroke HIT's key role in facilitating successful PPI within the stroke pathway reconfiguration has created learning for Bristol Health Partners Academic Health Science Centre (AHSC) and for the wider health and care system. The case study has identified enablers to this success.

A positive culture of PPI

Bristol Health Partners requires every HIT to work actively with public, patients and service users with relevant lived experience, and their perspectives are viewed as central to the successful development and implementation of health improvements. Those involved in the Stroke HIT's development, were also involved in the stroke pathway reconfiguration from an early stage by virtue of their work in stroke services, and so were well placed to promote PPI once the HIT was fully developed and approved by Bristol Health Partners. This meant there was a strong culture of PPI in the design phase of the pathway reconfiguration.

The Stroke HIT Directors were already working with PPI networks but their decision to adopt a Peer Director model gave prominence to the role of PPI and displayed a strong investment in this – particularly as this model was a departure from the usual mechanisms for PPI adopted by HITs. The model was then strengthened by the formation of the HIT Service User Group as this could reach a wider audience and broaden consultation on the reconfiguration. Arguably, this model was influential in driving and enabling PPI impact on the pathway redesign. As key members of the HIT leadership, the Peer Co-Directors and Service User Group Lead were expected to be part of the Stroke Reconfiguration Programme Board[5] which served as formal recognition that the HIT would be the vehicle for public involvement in the pathway reconfiguration work.

[5] Whilst one of the Peer Directors and also the Service User Group Lead were already part of the Stroke Reconfiguration Programme Board through their PPI roles elsewhere within stroke services, once the HIT became involved the second Peer Director was invited to join also.

The HIT public contributor impact on the reconfigured stroke pathway was further enabled by changes in leadership within the healthcare system locally during the reconfiguration which led to culture change and a greater emphasis on public engagement.

Being receptive to new ideas

The public contributor work on the stroke pathway has reinforced a strong culture of PPI within the HIT leadership team, which in turn has helped HIT public contributor impact on the pathway reconfiguration. The supportive working relationships with others in the HIT, and the ability of the HIT Directors and leadership team to respond to the voice of lived experience, have been influential. Public contributors spoke of the commitment and drive of the clinical HIT Director and his receptiveness to new ideas. From his perspective, the HIT Director tells how listening to people about their personal experiences has greatly enhanced his and others' understanding of how services might be designed to solve current problems, improve how services are experienced by users, and enhance clinical outcomes. This was important as he and other HIT Directors were involved in all aspects of the stroke programme planning and were often driving forward decisions on the redesign.

This partnership, involving listening carefully to people's experiences, understanding how these might be improved through better service design, and reflecting these suggestions back to service users for refinement and agreement, has been key to the success of the PPI and co-design process. For example, the clinical HIT Director's thinking on ongoing rehabilitation and support after stroke was transformed after hearing public contributors' views, experiences and self-management strategies; his interest helped to support the changes introduced to this part of the pathway and continues to motivate his desire to improve integration between rehabilitation and social care services.

Understanding the practicalities

The necessity to hold meetings online following the start of the pandemic had the effect of facilitating and improving public involvement in the reconfiguration. It made meetings more accessible by overcoming the physical challenge of getting to meeting locations without good disabled access or where these were some distance

away. It was also easier for public contributors to take part without the effects of their stroke being too noticeable. This was felt to be empowering for some public contributors. Whilst for the public contributors in this case study the move to remote working was viewed as beneficial, it is important to recognise that not everyone has the skills, confidence, or the technology to attend meetings online and there is a need to remain conscious of digital exclusion. From this case study, it has emerged that alongside meeting accessibility, factors such as who is chairing (and their experience of PPI), taking care over the use of acronyms, and having continuity and organisational memory (when there is organisation and staff change) may also affect the level and nature of involvement in meetings.

All concerned agreed this work has highlighted the need to have a clear and accessible process for public contributor reimbursement in place with an appropriate rate to acknowledge their time and contribution. Public contributors referred to the difficulty of claiming for the full extent of their time spent on the pathway reconfiguration and being prepared to give time without financial reward. There is a need to be clear from the start about the amount of time required as this can be considerable, as well as the mechanism for claiming this. One public contributor spoke of the conundrum of needing to be realistic without deterring people from getting involved. Finding public contributors with staying power and tenacity is important. However, it is also important that public contributors feel able to say 'no' when the demands of the role become too much. A clear process for checking in and communicating with public contributors is also important. As the HIT public contributors were working with more than one organisation, the CCG Insights & Engagement team were concerned about overwhelming their time. It was suggested a key point of contact who could provide an overview of what was being asked of them across the different organisations, would be useful.

An appreciation of the extra time required when working with people affected by stroke because of cognitive or communication problems has been important. The CCG commented on the need to account for this extra time at an early stage to avoid challenges in maintaining timescales and meeting deadlines.

Effective recruitment

As well as lived experience of stroke, the HIT Peer Co-directors and Service User Group Lead have highly relevant knowledge and skills to draw upon from their professional backgrounds in education and in health care. This has undoubtedly been significant in terms of what they could bring to the pathway reconfiguration and the impact they have made. The HIT leadership decision to conduct a formal recruitment process involving interviews was key to finding a combination of experience and personal qualities that would work for the HIT Peer Co-director roles. For instance, an understanding of the wider context and the challenges faced by decision makers, and an appreciation that, while an expert on their own particular experiences of stroke, one person cannot effectively represent the whole diverse range of stroke survivors and their experiences.

As well as ensuring suitability for the role, it was felt the interview process added legitimacy to the HIT PPI. The HIT also recognised the value of involving people who have a specialist knowledge of PPI in the interview process - in this instance a member of the People in Health West of England team. In this situation, one of the successful candidates also had specialist knowledge as a founder member of the National Co-ordinating Centre for Public Engagement (NCCPE). The recruitment of people with experience of working with other organisations providing stroke support was an additional enabling factor. Two of the public contributors had experience of working with staff and service users at Bristol After Stroke and one was a serving Trustee. This helped in getting the Stroke HIT Service User Group off the ground.

However, personal qualities have also been significant in enabling successful public contribution. In this case, the passion and determination to 'get the job done' has helped the Co-Peer Directors and Service User Group Lead to stay actively involved over the lengthy timescale of the pathway reconfiguration. Although their own experience of stroke services was a factor in their desire to bring about change, they also had a desire to represent the experience of stroke patients and survivors in general and not simply focus on personal experience:

> *'..you have to try sometimes to divorce yourself from your own lived experience and offer a more general patient experience, the more contacts*

you have to do this the better, use online forums to explore issues and become familiar with topics.'

As one of the Peer Director's pointed out, because all strokes are different public contributors cannot act individually as representatives for all stroke survivors but are experts by experience in their own particular stroke and can offer expert advice about their particular individual experience. The Co-Peer Directors and the Service User Group Lead had experience of a variety of conditions and types of strokes, as well as experiencing varying levels of physical disability. It was important to have access to this range of experience and future learning from this suggests that one public contributor would be insufficient, whilst a group of contributors with different experience working as a team would be optimal. Having a group of people with different experiences working as a team, with access to a broader, more diverse range of experiences through related groups and networks, supports the aim to represent the totality of service user experience more effectively.

Having more than one public contributor role within the HIT has also been beneficial to the pathway reconfiguration on a practical level. The Peer Co-directors and Service User Group Lead have worked as a team by providing support to each other and cover at various meetings or presentations when someone is unable to attend. It could be argued that being part of a HIT has facilitated this teamwork.

The opportunity for Public Contributors to reflect

Capturing the reflections of public contributor involvement in a change process is also a key part of the learning. The reflections of the Co-Peer Directors and the HIT Service User Group Lead on their involvement in this pathway reconfiguration and what it has meant to them personally was reported in a recent Bristol Health Partners AHSC newsletter piece[6]. It offers valuable insight into how they got involved and how others with lived experience of a health condition can make a difference too.

[6] Bristol Health Partners newsletter article (3 March 2022) We're the experts on how our conditions affect us" - How public contributors helped improve local stroke services | Bristol Health Partners

What next? How to build on this work?

This model of PPI has worked well in the planning and development of the stroke pathway reconfiguration. While the Stroke Reconfiguration Programme Board will change, the Stroke HIT, and the HIT public contributors will continue to be involved in the new pathway implementation.

The value placed on HIT PPI input is reflected in the CCG's invitation to the HIT to provide PPI support to the implementation, evaluation and ongoing oversight of the new pathway.

Informing the implementation of the of new pathway

The success of the PPI provided by the HIT as the stroke business case was acknowledged by an invitation to the HIT to put forward a proposal for how ongoing PPI might look. The principles put forward in this proposal have been approved and included in the Terms of Reference (TOR) for the Stroke Implementation Board.

> *'The Stroke Implementation Board recognises and values the input and impact of service users and patients with lived experience in supporting the Programme to ensure that all elements of the new clinical pathway for stroke care will operate safely and seamlessly for patients and their carers. In working with service users through the Programme we will ensure that service user representatives are:*
>
> - *informed about and involved in the implementation of the services described in the Healthier Together Stroke Programme Decision-Making Business Case (DMBC), to ensure that the implementation is in accordance with both the written descriptions and spirit of the changes within this business case,*
> - *feel supported to provide their input despite disabilities such as communication difficulties,*
> - *closely involved in decisions taken by providers and commissioners where they feel that stroke services need to depart from those described in the DMBC*
> - *communicated with transparently about implementation plans, as valued partners in decision-making*
> - *feel valued and listened to, particularly when difficult and important decisions need to be made or when their views conflict with those held by others.'*
>
> *(Stroke Implementation Board, Terms of Reference, May 2022)*

Playing a lead role in the evaluation of the new pathway and monitoring of stroke services

- The public contributors will inform the evaluation of the new pathway and its ongoing development. The CCG invited the HIT public contributors to sit on a group to determine the outcomes to be used in evaluating the new pathway using a value-based framework, with a view to stroke being a template for similar work in other conditions and to allow value-based commissioning in the future.

- As part of the plans for evaluation, the HIT PPI will continue to act as a platform for feedback. The HIT will partner with Healthwatch across BNSSG to feed into the stroke programme over time by collecting and providing service user views, e.g., setting up a website for service users comments, and providing regular reports on service user experience. It continues to build on its relationship with social care commissioners and providers, as well as public health services.

Those leading on the evaluation commented that the HIT PPI model has been 'a truly excellent approach for routinely getting feedback' and that having HIT public contributors involved has made it easier to reach out to others to review plans for evaluation and routine monitoring of stroke services.

Widening PPI within the new pathway

The HIT is seeking to improve its PPI in terms of diversity and being able to represent all groups affected by stroke. For instance, it has plans to look at childhood stroke in the future. It also has plans to engage with local organisations, such as those representing ethnic minorities and other seldom heard groups, to advocate their views and enable them to engage with local health and care commissioners. The HIT has also invited local Healthwatch organisations to be represented within the HIT Executive as a way of strengthening the public voice within the HIT and the regional lead is now on the Executive.

Providing research and staff education to support innovation

The HIT will continue to deliver and collaborate in relevant research to support innovation within stroke services, particularly where this is relevant to stroke services in BNSSG. The HIT public contributors are very much involved in the HIT's research and innovation workstream and have contributed to successful research grant applications for innovations to be adopted. Public contributors are also actively involved in the HIT's education and training workstream, and in service improvement initiatives.

In summary

This case study highlights how the HIT has helped the reconfigured stroke pathway to be grounded in what matters most to people affected by stroke and delivering the best outcomes for patients. The importance of giving full recognition to the value of evidence from people with lived experience is reflected in a recently published national statement about Shared Commitment to Public Involvement, which will be published in March by the National Institute for Health Research and the Health Research Authority.

Furthermore, the HIT has provided continuity of key clinicians and PPI and provided organisational memory throughout the pathway reconfiguration, and in terms of next steps this will continue to be beneficial. The success of the Stroke HIT PPI model may also be inspirational for the new BNSSG Integrated Care System (ICS). As Chris Naylor at the King's Fund recently commented in his blog on integrated care systems:

> '*Finally, ICSs need to become much more sophisticated at using insights from local people including patients, service users and families. ICSs cover large geographies so there are limits to how much granularity they can go into, but there need to be channels through which locally gathered intelligence can flow from neighbourhood to place to system level. As we have argued in previous work, the best way to understand whether integration is delivering results is through the eyes of people using services.*' (Naylor, 2022)

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(May 2022)

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