WEST CUMBRIAN'S VOICE FOR HEALTHCARE

CO-PRODUCTION: VIEWS FROM VOICE MEMBERS

INTRODUCTION

Co-production was set up in the North Cumbria health area following the 2016-17 *Healthcare For The Future* consultation. The aim was for community members to work together with the NHS to jointly design good quality health and care services. As the process has been in place for more than a year, we consider it worthwhile reviewing how it is working. We offer below our thoughts on this as a basis for discussion.

HOW DO WE KNOW CO-PRODUCTION IS WORKING?

To show that co-production is working and for it to succeed in the long term there should be concrete evidence of where community involvement has made a difference. So far there is little or no visibility of how lay input has impacted on decisions.

What successes do we think there have been? Can we go back as far as the Success Regime? Strong community representations were made for retaining consultant led maternity at West Cumberland Hospital, including a case argued based on medical research papers which showed the risks of long journeys in labour. It is not clear to what extent the research-based arguments influenced decision-making, but if they did this is an example of co-production as members of the public drew material to the attention of the Success Regime when they had apparently been unaware of its existence. This wasn't losing an argument – it was real listening and a good example of co-production.

Outside of the co-production process Voice members have worked with NHS representatives on issues such as patient experience. This has been productive in the past. It is dependent on both continuity of staff and co-operative working with community to continue past good work and make progress.

STRUCTURE

We believe that there is value in having a small over-arching steering group which draws together threads, promotes cross-group learning and provides a strategic focus for the work. There is some confusion over the coordination role of the Working Together Steering Group (see that section).

NHS representatives have referred to discussions (we assume within NHS organisations) on preventing duplication of work across groups, but there are common threads, like ambulance services and care at a distance, which are integral to work done by most of the groups. Duplication is not only unavoidable, it can have advantages in seeing issues from differing points of view. Although a group for stroke services is shown on the CCG website it does not really exist. This is dealt with later in the section on stroke.

We are not aware of any co-production process in the development of Integrated Care Communities and look forward to learning how co-production is being incorporated into ICC planning. Eighty-eight people have been invited to the *Shaping Health and Social Care* engagement event on 22 January 2019 but this list contains less than 10 representatives from patient or other voluntary groups.

NHS INVOLVEMENT AND CAPACITY

We recognise that co-production is resource hungry and we have some concerns about the administrative and management capacity of the NHS to deliver, especially as we are asking for a strategic group and for co-production on stroke services.

The North West Ambulance Service is critical to many of the services under discussion and their active involvement in co-production is essential. We appreciated their presentation at the November 2018 West Cumbria Community Forum, and the agreement to provide breakdowns of ambulance response times for smaller areas than the currently available Cumbria-wide figures. We look forward to their continuing engagement in the Forum and in other groups.

COMMUNITY PARTICIPATION

Co-production has the potential to help to provide solutions to problems and ultimately develop a health model which provides equal and equitable services for our remote urban/rural communities. An aspiration is to create long-term partnerships with lay members who have the skills, confidence, support and experience to contribute as equal participants, taking part in shaping continuing improvement and tackling future changes and challenges at the earliest possible stage,

Lay members should be encouraged and empowered to play an active part in shaping agendas and taking responsibility. Could some meetings be chaired by lay volunteers or people from within the NHS, but without major responsibilities for service delivery to avoid possible conflict of interest? Would volunteers for such roles be available in the light of low community participation? Is the relatively new Health Partnerships Officer making progress in drawing in the third sector? Can more be done by the co-production secretariat provided by Healthwatch? Will the involvement of the Institute for Voluntary Action Research resolve some difficulties on stroke service design? We don't have the answers to these questions but would welcome open and honest discussions.

Groups are generally formed from the 'usual' community people, campaigners and local government representatives. We realise how difficult it is to draw people into the process. Knowledgeable members of relevant third sector bodies should be actively recruited. We hope that the liaison work with the third sector now being carried out by the Health Partnership Officer, as well as the engagement plan under development by CPFT governors for the North Cumbria Health and Care System, will bring benefits in drawing in appropriately knowledgeable and constructively interested people.

WORKING GROUPS

We give below our thoughts on how the co-production groups have developed.

Children's

There is a strong drive to work together in this group. Health care, public health, local government and community members have united well, bouncing around ideas, listening to one another and taking suggestions on board. Successful achievements have been: work on the whole system asthma pathway; promoting the child health app; agreement to involve children and young people in practically reviewing the Short Stay Paediatric Assessment Unit at West Cumberland Hospital. Other ongoing work is that the Patient Experience team are to be involved in the 15 steps challenge, People First have offered to help with contacting children's groups to get adolescents/secondary school volunteers involved and the group has been asked to support the development of the Health and Wellbeing Action Plan on Obesity. The group has made suggestions on taking the questionnaire on SSPAU back to children/families. Although this was not covered in the October 2018 meeting, we hope this will provide further evidence of co-production success when complete.

Although these are all signs of positive progress, the main community input has been through the 'usual suspects' and at the latest (November 29th) meeting the group recognised the lack of wider community involvement meaning that true co-production is still missing. The group is to reflect on and discuss this next time. The issues addressed to date have only included some service changes, such as SSPAU developments, and community input to that has been limited. Any impact of such input would be hard to describe as yet and will hopefully be part of future discussion in January.

A work programme into late 2019 is being developed to include issues such as obesity, infant mortality, mental health, housing and poverty. A strapline for the group has been agreed:

"*Working Together to get better outcomes for Children and Young People's Health".*

Community Hospitals

We haven't taken part in this group as the community hospitals concerned are outside of our geographical area. We wonder if there are lessons to be learned from the work of this group (see comments on an overarching steering group under *Structure*).

Experience of Care at a Distance

The group is working well in terms of co-production. Group members, whether lay or professional, are listened to with respect and work is shared – not just left to the professionals. There is a will to produce positive changes in the experience of care for people who are treated away from their local area.

There are some difficulties. The frequency of meetings has been halved, with no extra time allocated to the length of each meeting. We believe that nine hours a year is inadequate to deal with the complex challenges raised by delivering care at a distance, not only for patients but for family members and carers.

Continuity has been another difficulty. Management of the work/action plan has been challenging in the changing management environment. An example was the proposal to investigate the possibility of a shuttle bus between the two hospitals. The item fell off the agenda until a lay member asked about it. In another case positive work on the transfer experience questionnaire seems to have fallen off the agenda in terms of community input. These issues may both be due to a change of

chairman and other members with a resultant loss of 'corporate memory'. It would be good to have continuity of chairmanship and supporting staff from NHS organisations.

We are not here challenging decisions, but making the point that items disappearing from the agenda or workplan without explanation, and with insufficient follow-through of ideas discussed in other, more open, meetings creates frustration and results in a loss of trust. This is not just amongst group members, but also members of the public who follow issues which matter to them. When they hear or read about possible solutions to problems and then hear nothing more, or are not updated when they ask, they become more cynical.

ECAD has a critical role in the design of services in this geographically challenging area and it is important that the group is involved early in the planning of any changes to or development of new services so that the full impact of distance can be evaluated.

Succession planning is important. There are only two lay members, one supported by Healthwatch. Recruitment of the next generation should be considered.

Recruitment and Retention

Challenges in accessing some information around recruitment and retention issues has slowed progress and frustrated members. We are told this has resulted from changes to the structure and leadership of the HR Department and that members should see improvements.

The group has been briefed on the new branding and the re-energised joint recruitment drive from the hospital, community and ambulance trust. There has also been some opportunity to suggest improvements and additions to the recruitment armoury of the local NHS, but there has been frustration around being able to fully understand and get involved in recruitment to medical posts which challenge the sustainability of services, to access information about how job roles are described and advertised, and to tackle issues around retention.

The group has organised and held a welcome event which resulted in a video now used in all recruitment activities, more recently the group has been given the chance to input into the workforce strategy and supported a nurse recruitment visit to the hospital.

We hope that increased support from senior HR leaders and senior nursing leaders is starting to improve a slow and difficult start.

Stroke Services

We welcome an HASU in Cumbria and accept Carlisle as the location, but we believe there has been avoidance of the challenges posed in Copeland. There is no co-production process to cover the challenges raised, investigate possible mitigations and co-design stroke services. We have pressed for more community involvement and put forward a paper proposing several possible mitigations.

So far, the single mitigation under public discussion is awareness and prevention under the new North *Cumbria Building Health Partnerships*. This is a positive step in bringing together services and communities to reduce the incidence of stroke and Voice members intend to play an active part. However, many of the concerns of people in West Cumbria, particularly south Copeland, lie in what will happen if they or someone close to them has a stroke in an area so far away from care.

The stroke meeting in Copeland on 19 June was heated and was unable to begin discussions on implementation challenges. The fears of the population in Copeland are real. The road and public

transport infrastructure are very poor and travel times to Carlisle from south Copeland are more than an hour. Target national ambulance response times (75% of life-threatening calls responded to within 8 minutes) are treated with local cynicism. There are reports of improvements in ambulance response times but no published figures other than averaged figures for Cumbria. We look forward to seeing the breakdown of figures mentioned in *NHS Involvement and Capacity* above.

The Business Case on Stroke services, particularly sections 2.14 and 2.16[1] make recommendations, for instance:

> ***Risk:*** *Failure to be able to demonstrate reasonable co-production with the community.*
> ***Proposed Mitigation:*** *Development of a programme of co-production into implementation plans as outlined in the CCG Governing Body supported by the Stroke Association, with public workshops and individuals providing patient insight into all aspects of the implementation. Membership and Attendance at Stroke planning meetings.*

We see no evidence that these recommendations are being carried out and look forward to the beginning of real community involvement in a Stroke co-production group.

Working Together Steering Group

We're not clear on the remit of this group. It began as a group looking at the testing of Maternity Option 1 to maintain consultant-led care at the West Cumberland Hospital and the development of an inpatient paediatric unit with Short Stay Paediatric Assessment Unit at Whitehaven. However, the group receives feedback from other co-production groups, suggesting that it is acting as a steering group for the co-production process. Perhaps it has evolved into this or that confusion has arisen from the title of the group and the fact that there is no overall co-production steering group. There is good attendance from NHS management but a reducing involvement from members of the public. We believe this group does not act as a decision-making group, but only as a mechanism for feeding information to people and having a discussion. As mentioned in *Structure* above, we believe it is time to review the co-production structure and put in place an over-arching strategic steering group.

Maternity Voices Partnership (MVP)

The background and history to user/community involvement is relevant to understanding this area of co-production. It benefits from the drive, commitment, knowledge and experience of the West Cumbria MPV Chair (who also sits on the MPV National Committee). There is also a history of active involvement through Maternity Services Liaison Committees in the North Cumbria area since the early 1990's. The 2006 lay report and the 2007 Community Maternity survey were high points of involvement. The former was an example of co-production which helped to shape outcomes.

MVP's are part of current NHS *Better Births* Policy, with a national expectation that they are implemented and effective as a local co-production forum. The West Cumbria MPV has a financial resource to cover some Chair time, travel and childcare expenses for service users, promotional and survey work and website development. It can also tap into the national MPV network (which the West Cumbria Chair was involved in developing). These are all enablers for lay voices and for co-production and we would expect this area of co-production to be a forerunner for the others.

There are examples of good involvement with MVP members in maternity developments, along with evidence of growing service user engagement in co-production/co-design activities. However, there is still a need to identify clearly how that involvement has made a difference. The MVP is not always

[1] http://www.northcumbriaccg.nhs.uk/about-us/how-we-make-decisions/Governing-Body-Meetings/2018/2018-april/bulk/07implementationreferencegrouprecommendations.pdf

involved appropriately in processes from the start. It has longstanding concerns about Honister facilities, reflected in service user experience feedback. Promises of full involvement following the CCG Safety & Quality Group visit to maternity in February 2016, didn't happen. More recently the MVP has been involved in looking at the 5 year forward plan for Honister improvements. An involvement process is essential to address the needs of service users.

Remote Consultation Development Group (was Telemedicine Working Group)

This group, initiated at the first Working Together Group in September 2017, started by scanning the use of telehealth locally, in the UK and internationally. Local initiatives were the link between the obstetric unit at WCH and Newcastle, the CHOC piloting of *Attend Anywhere* (AA) remote consultation and the CPFT use of video links for mental health services. AA was developed in Australia and is being adopted internationally, including for remote areas of Scotland. Contact was made with the respective leads and other persons already engaged in the field of telemedicine/remote consultations. This resulted in an expanding team of people representing NCUHT, CPFT. UClan, CHOC, CCG, NHS Support Unit and members of the Working Together group.

Since inception the group has grown from 7 to 27 people, drawing in a great deal of expertise. With Deb Lee as clinical lead and driver, the group expanded an existing list of proposed pilot schemes to include more clinical categories and meetings were organised within the acute trust to bring in clinicians. The NHS Support Unit helped to draw up a business plan for 63K funding from NCUHT. Each scheme must be shown to be efficient, to be acceptable to patients and other users, and to save money, or at least be cost neutral. The success of this group has been built on the initial learning from the wider telehealth environment and on the drive of very committed people. Co-production has brought together expertise from many areas, some of them previously working in silos, and the lay membership has continued throughout. Funding for pilot schemes has been agreed.

CONCLUSIONS

Co-production can help to build bridges and develop constructive ways of working together to solve problems. We understand the challenges, particularly as we began from a low point of community fear and lack of trust in the NHS and, in the NHS, people who felt under attack, often personal attack during the public consultation and at times after that. Co-production groups have been building bridges and developing constructive ways of working but with varying levels of success. We propose:

- A co-produced review of the process and structure using the West Cumbria Community Forum to identify improvements. Support has been offered by CLIC
- Sufficient resources to support and enable co-production
- Reports on where community involvement has changed NHS thinking and plans
- A discussion amongst community members, Health Partnership Officer and NHS representatives about how to broaden and improve involvement
- The publication of a short, user friendly, co-produced strategy document which confirms NHS commitment to co-production and how the process works