healthwatch Cumbria

Community Hospitals and Co-Production

February 2018

your voice counts

Preface

It is essential to make clear from the outset that throughout this project, Healthwatch Cumbria (HWC), has been careful to adhere to its independent role. In the work, HWC aims to present an unbiased assessment of the experiences of those people who participated in the Community Interest groups (or Alliances) which were directly involved in the co-production process surrounding the decision to remove inpatient beds from the community hospitals in Alston, Wigton and Maryport. HWC sought not to be critical but rather to act as an advocate for the process of co-production.

The project has not focused on the technical aspects of changes to service delivery in the catchments for Alston, Maryport and Wigton community hospitals or the rationale for the removal of beds. Rather, the project aims to shed light on the state of relationships between the Alliances and the NHS, to provide informed feedback and improve the co-production approach for all involved.

The role of HWC is to look for ways to ensure that all voices are heard and that, moving forward, relationships between the health and care sector and community groups, and opportunities for people to be directly involved in the service design and delivery are enhanced. The challenges facing the health and care system in Cumbria remain complex and profound; resolving these so as to achieve the best possible outcomes is heavily dependant upon the extent to which decision making is able to draw on the collective knowledge and wisdom that resides in all corners of society. The responsibility to make this happen is borne by all.

Introduction

About this project

During August and September of 2017, the Integrated Care Community (ICC) Steering Group discussed the progress made surrounding decisions about the future of Alston, Maryport and Wigton community hospitals. At this time, although the tone of discussions was generally positive, some members of the public were still expressing concerns over the implications of proposed changes that they considered unaddressed.

These concerns were manifest during some of the engagement sessions and public meetings during the Success Regime. HWC staff had witnessed some angry exchanges which, at times, had detracted from the potential for a productive, collaborative working relationship to develop between community groups and the NHS.

HWC was also aware that, despite these difficulties, the NHS remained strongly committed to working according to the guiding principle of ‘co-production’, placing it at the core of the ongoing development of ICCs and in the implementation of the full set of decisions that had been taken by Cumbria Clinical Commissioning Group (CCG) following the Healthcare for the Future consultation. The aim of co-production is to ensure that community groups, representing the public in areas affected by changes to service

delivery, are incorporated as partners in decision making. For this to take place effectively it is essential that constructive dialogue is the defining feature of relations between the NHS and community interest groups.

HWC resolved to conduct a focused piece of work to assess whether people involved in the Alliances and the NHS shared an understanding of the effectiveness of co-production in each of these three locations. If significant differences existed, it would be important for these to be accounted for in some way to reduce the risk of misunderstandings that could be harmful to future collaboration.

The aims of the project were defined to be:

i) To examine the experiences of representatives of the Alliances of the co-production process, with a view to making recommendations as to how this can be strengthened

ii) To identify any specific issues about aspects of future service delivery that participants perceive to remain unaddressed

Co-production and community hospitals

As part of the CCG's engagement process the principle of co-production was introduced relating to each service area, including community hospitals. Co-production is defined by the CCG as a 'means of drawing on the knowledge, ability and resources of service users'[1]. Specifically, the co-production framework aims to be open to all, flexible in working with communities, to account for relevant feedback and foster clear and transparent communication.

Community interest groups concerned with community hospitals have a long heritage. Leagues of Friends can in some cases trace their origins back to the 1950s and 1960s, when they were initially formed to act primarily as fundraisers. Over time, they became increasingly invested in the future of the hospitals, such that in 2006, when major changes to community hospitals in the region were first proposed, they were naturally prominent voices in the discourse that ensued. David Maclean, then the MP for the Penrith and the Borders constituency, recognised the democratic and intellectual value of their contribution; to amplify this, he facilitated their pooling of resources in the formation of a Joint League of Friends, comprising representatives from each area.

This increased level of organisation cemented the status of these groups as well organised, informed and articulate representatives of the interests of community hospitals. Held in high regard by the public, they were key community stakeholders as subsequent events unfolded. Some representatives have said that they were not sufficiently engaged as participants within the Success Regime and that this may have influenced their continued concern about their involvement after the consultation and during the implementation of the decisions.

[1] North Cumbria CCG, *Healthcare for the Future Update: NHS North Cumbria CCG Governing Body*, 4th October 2017, p6.

Currently, co-production in the context of the three community hospitals that are the subject of this work consists of representatives of the NHS working in partnership with Community Hospital Alliances in each area. These alliances are the formal descendants of Leagues of Friends, with roles, responsibilities and status within decision making that are now more clearly defined, at least in principle. There is a general recognition that working together with local communities will enhance the implementation of Integrated Care Communities (ICCs). Successful Integrated Care Communities will provide efficient, 'joined up' healthcare, more community services and will help people to manage their own health.

Further information on the areas and GP surgeries covered by the ICC's are available at:

www.northcumbriaccg.nhs.uk/iccs

The Success Regime

Representatives of HWC talked to many people during the Success Regime and were aware that frequently it was perceived as a negative initiative designed to reduce and/or remove services. The reason for its inclusion as context here is that it demonstrates the extent to which community engagement has improved.

The NHS set up the West, North and East Cumbria Success Regime in autumn 2015 to work with local NHS organisations, communities and national experts to address major challenges in health and social care services. It was tasked with developing a workable plan to create a sustainable healthcare system for the future. It culminated in the '*Healthcare For The Future'* consultation, which ran between the 26th of September and the 19th of December 2016.

Following the consultation period, on the 8th of March 2017, CCG presented a number of options for the future of six areas of health services. There were four options regarding community hospital inpatients. The NHS expressed a preference for a situation in which no community hospitals would be closed, but inpatient community hospitals beds would be consolidated into six sites. In total, there would be 104 inpatient beds spread between Brampton, Cockermouth, Keswick, Penrith, Whitehaven (Copeland Unit) and Workington. In all four options, inpatient beds would be removed from Alston, Maryport and Wigton community hospitals.

Respondents were asked to rank the order in which they preferred the options and why, and were asked for proposals of their own. Members of the public were also encouraged to send in their views on these options in different formats including letters and e-mails. In total, 45% of respondents identified preferred options; 36% chose not to rank any options but added comments to explain why they did not agree with any of the proposed options and 19% did not answer either part of this section[2].

A substantial number of the comments in the questionnaire were unsupportive of the proposals with many saying that they had not stated a preferred option because none of

[2] *Healthcare for the Future in West, North and East Cumbria Consultation for NHS Cumbria CCG and Success Regime West, North and East Cumbria Report from The Campaign Company (TCC)*, February 2017

the options were suitable or acceptable. Others declared that they considered their stated preference to be the 'least bad' option and expressed concern or disappointment about the fact that the overall number of inpatient beds in community hospitals was to be reduced.

Some media coverage portrayed the Success Regime as a futile exercise, a gross misuse of public funds and articulated the general feeling that public consultation had, in this instance, been employed merely as a box-ticking exercise to provide retrospective validation of decisions that had already been made. In the short term, this was extremely damaging for co-production as it reinforced a commonly held existing public suspicion that any changes to NHS services would result in their degradation. This fuelled antagonism, which at times was witnessed during public meetings.

However, it must be remembered that at the time, co-production was a relatively novel concept in healthcare governance and many of the representatives of the health and care organisations involved had little experience of meaningfully accounting for and responding to the ideas or concerns of the public.

Despite the mixed views about the effectiveness of the Success Regime, it has provided extremely valuable learning which can now be used to help shape and inform the emerging co-production process.

This leads to a quote received from a member of the public during the engagement period of this project:

'Surely [co-production] starts with an understanding of what this means at all levels amongst health decision makers, health workers and the community; an understanding of the value of it, an understanding of community assets and an understanding of the resource and infrastructure required to deliver it'

Methodology

To satisfy the aims of the work, two types of engagement were conducted:

i) An online survey
ii) A focus group in each location

Survey Method

The purpose of the survey was to gather individual feedback from those people who had experience of being involved in the community hospital co-production work and to provide a general overview of their opinions of that involvement from a community perspective. The survey was broken into five subject areas, each of which covered a different aspect of the future of these community hospitals and the co-production process. These five subject areas are described in detail below.

The survey and an accompanying brief (Appendix 1) was disseminated through the email contacts of individuals identified as being heavily involved in each of the three Alliance Groups. Our information suggests that up to between 10 to 12 people normally attended

the co-production meetings Alston and Maryport and 6 to 8 (including health and care professionals0 in Wigton. It was not intended for the public, as the survey items explored in considerable detail various aspects of group activities. Members of the public without sufficiently detailed knowledge would be unable to provide comprehensive answers.

Prior to its release, the survey was circulated to [the CCG] for comment. Following this, a short paragraph concerning recent media coverage was removed from the introduction; Healthwatch Cumbria agreed that it could be perceived to be leading in nature and would not contribute to the intended constructive tone.

The survey was relatively long, consisting of a total of 44 items. It was assumed that respondents, having received the survey through Alliance Group communication channels, were likely to be sufficiently engaged with the issues to be willing to spend an anticipated five minutes completing the survey.

The majority of the survey comprised Likert type items, in which respondents are asked to rate the extent to which they agree or disagree with a particular statement. These comprised a mixture of positive and negative statements. Likert type survey items provide an overview of the nature and strength of feeling respondents harbour towards various aspects of the situation surrounding the object of study. In addition, a number of open text fields were included to give respondents the opportunity to express their thoughts with a greater degree of freedom.

The survey did not include any demographic questions. The reason for this was that the overall sample size was likely to be too small to conduct a meaningful comparative analysis between locations.

Focus Groups

The aim of the focus groups was to provide a setting in which to discuss in more detail and with greater flexibility the same subject areas of community hospital services covered in the survey (see below). These were collated into a set of discussion points that were to provide an underlying guiding structure to the focus groups (Appendix 2). Focus group facilitators were briefed that this structure was only to be loosely adhered to, so as to let the conversation flow more naturally and cover ground that it did not necessarily include. Prior to the focus groups, briefings were circulated amongst potential participants (Appendix 3).

Three focus groups were held, one each for members of Community Hospital Alliances in Alston, Maryport and Wigton. The intention behind this was to provide an opportunity for the research to identify issues specific to each location, which was beyond the capacity of the survey.

Survey and Focus Group Subject Areas

1: About the community group

This covered the history of the groups, including how they had changed over time, the number of people involved and the extent to which people are or have been involved. It included questions about the preferred means of communication used by the group and

the frequency with which they are used. It aimed to assess how dependent the groups are on the input of key individuals. Finally, it sought to gauge whether group members espoused diverse opinions or perspectives, or whether these were generally homogenous.

2: Information and knowledge

The primary purpose of this section was to gauge how group members perceived their communication with NHS organisations. This section is crucial as the flow of information between the community and the NHS is, arguably, the most important element of co-production. In addition to specific questions about the exchange of information, it aimed to gauge how well-informed respondents felt as individuals and how well informed they perceived their group to be as a whole. This section included items assessing how well-informed respondents think the general public are, and whether they support the agenda of the group.

3: Attitudes

This section aimed to explore the nature and strength of feeling that respondents have in regard to the current state of co-production. Survey items and focus group discussion points covered the level of optimism or pessimism towards co-production and perceptions of the level of understanding within the NHS.

4: Outcomes

This section aimed to identify specific issues that community group members feel to remain unaddressed. It also incorporated outcomes in terms of whether respondents considered whether their own perspectives, as well as those of the NHS have changed as a result of the co-production process.

5: Engagement

This section was relatively brief, requesting respondents to self-rate their personal level of involvement with the activities of the group, whether they intended to remain active in the future and whether they felt their contribution had made a difference.

Results

Survey Findings

The survey received a total of 17 responses (from a possible total of approximately 26). Please note that, for those reading this report in black and white, the top to bottom order of categories in the key for each chart corresponds to the columns running from left to right. Results are presented by subject area. Analysis is limited to observations of visible trends, as owing to the small sample size detailed statistical analysis would not produce meaningful data. To a degree, therefore, these results are open to interpretation; they are presented as a means of identifying areas that warrant further attention or discussion.

As a general point, it is worth noting that in the survey a number of comments clearly show that this project was seen by some respondents as an opportunity to express their grievances, illustrated by the following quotes taken from the open text fields:

> *'Do not take beds from Maryport hospital'*

> *'The hospitals are needed'*

Both of these come from individuals who self-identify as being amongst the least involved of the respondents, suggesting that considerable differences in perspective exist between those at the centre of the groups and those on the periphery.

1: About the community group

Level of organisation and number of members

Respondents overwhelmingly agree that their groups are well organised and that over time, this level of organisation has remained roughly the same or increased (see figures 1.1 & 1.2). The number of group participants is considered, in general, to have remained roughly the same (figure 1.3)

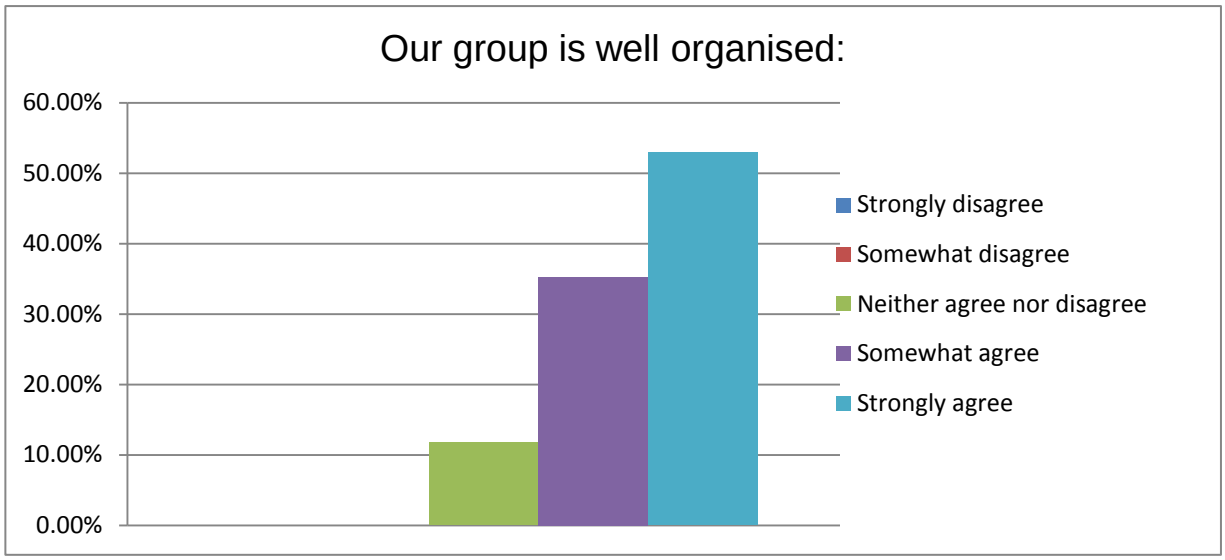

Figure 1.1

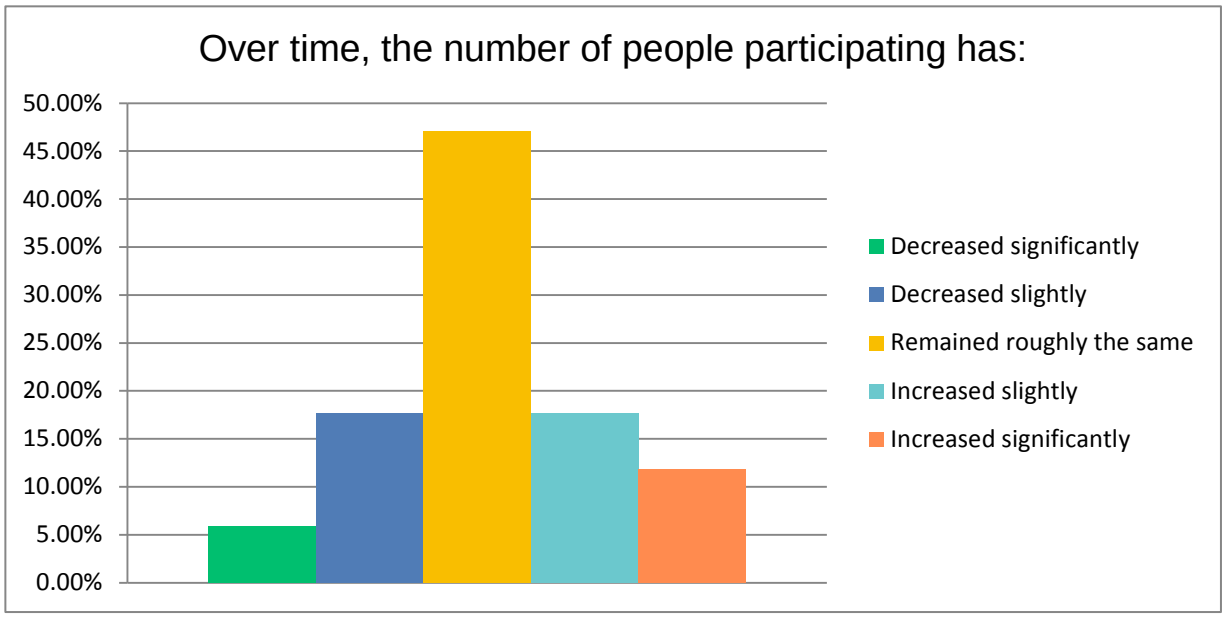

Figure 1.2

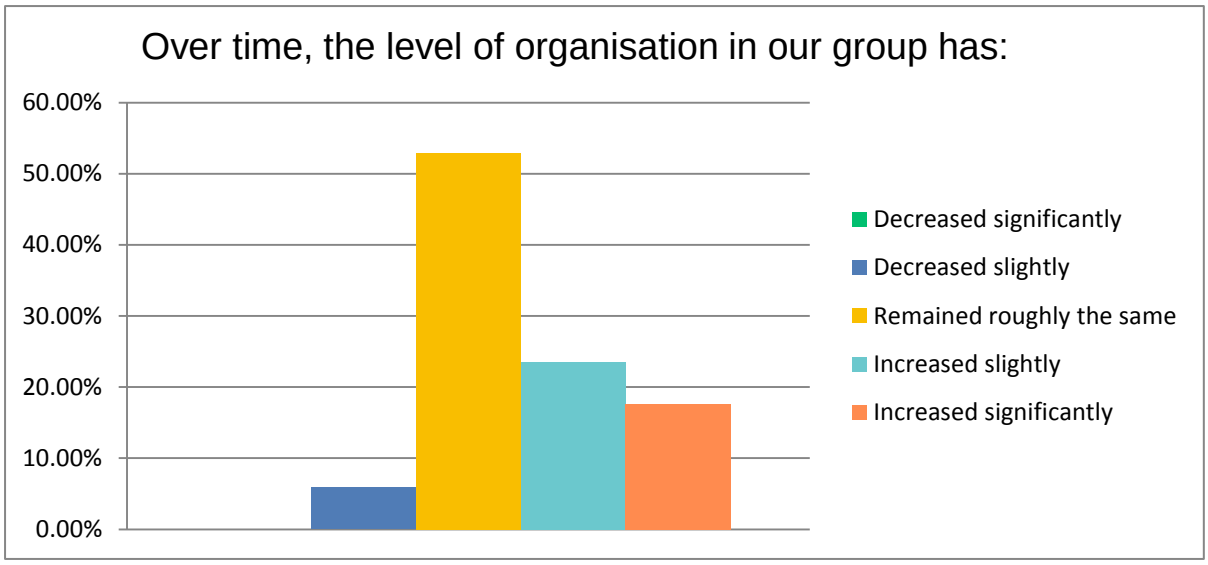

Figure 1.3

Preferred means and frequency of communication

All but two respondents had one or more responses indicating that they communicated in some way a few times a month or more, suggesting that the groups remain fairly well-connected. Email and Facebook were the most commonly used means of communication, but the means used by the largest number of respondents was face-to-face (figure 1.4).

Two comments were received in the 'Other' open text field. These mentioned regular meetings and workshops, to which stakeholders and members of the public are invited where appropriate.

Almost all responses (28 out of 32) for the survey item 'Please indicate whether the group's usage of these means of communication has increased or decreased over time' indicated that the frequency of communication had remained roughly the same.

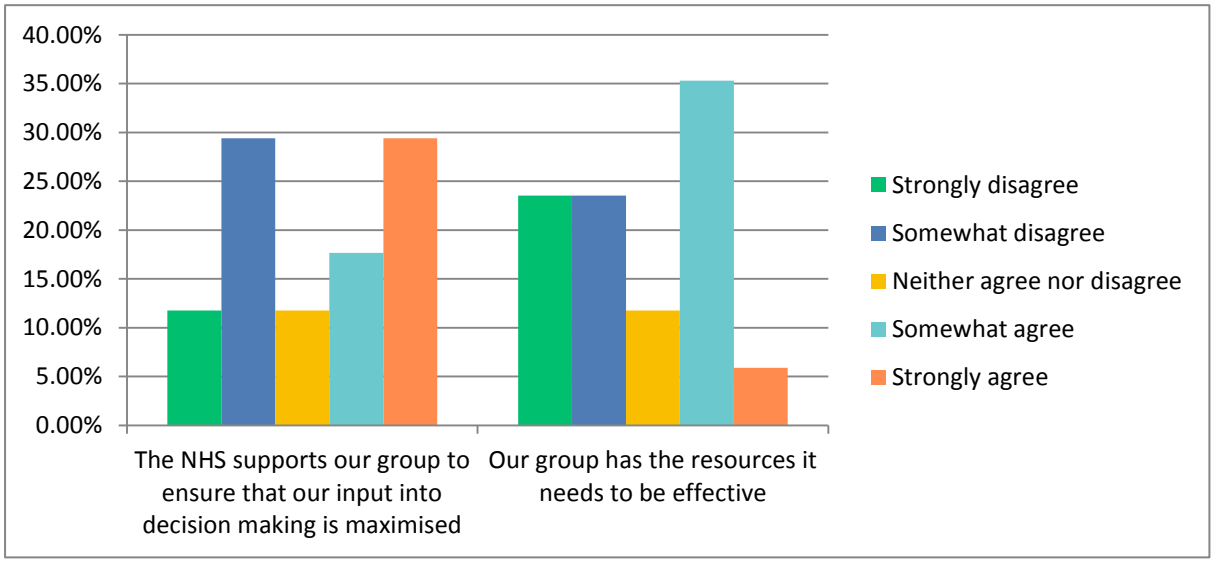

Figure 1.4

General features

16 out of 17 responses agreed with the statement 'members of our group share a vision for the future of healthcare in our community'. 14 out of 17 responses agree with the statement that 'our group can provide valuable input into decision making around healthcare provision in our community'

Responses to the other two statements in this sub-category were mixed (figure 1.5)

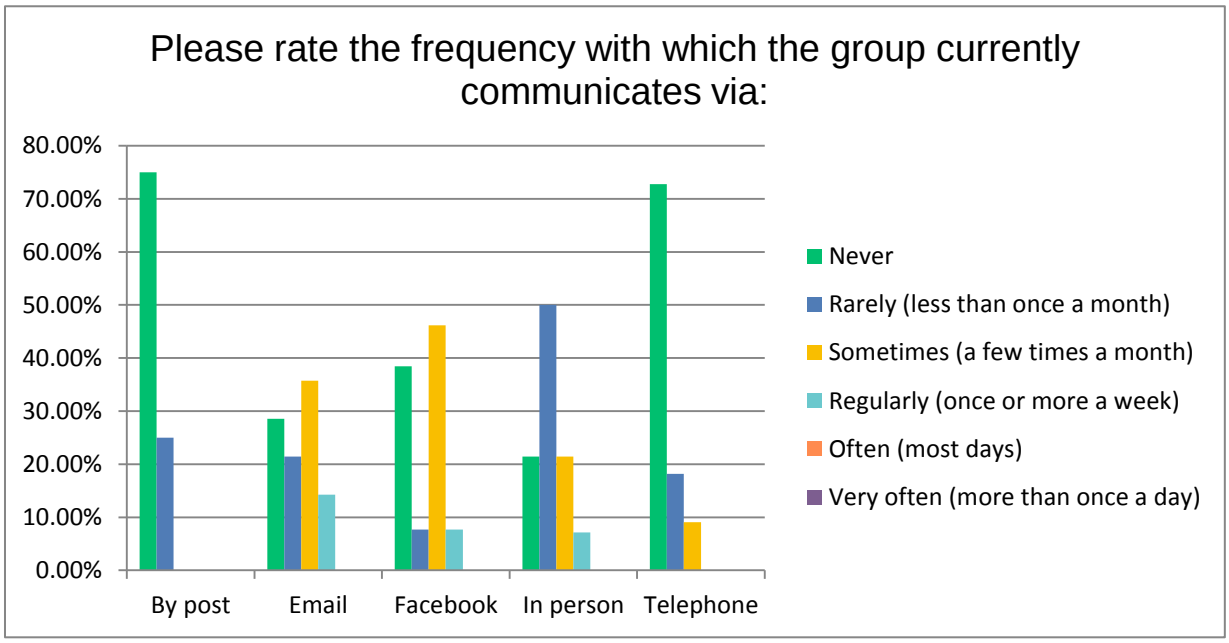

Figure 1.5

Open text fields

Responses to the question: 'what would help your group to work more effectively?' yielded the following themes:

- Better listening or communication by NHS organisations (7 comments)
- Stronger collaborative process, including rotating the chair of meetings between NHS and community organisations to equalise the balance of power within interactions (2 comments)
- Larger memberships (1 comment)
- Better publicity for group activities (1 comment)

In addition, two comments indicated that consensus has not been reached, effectively giving the answer that the NHS should abide by the wishes of the community.

One comment expressed significant optimism, following assurances from high level individuals in the NHS and their local MP that the commitment to include community groups in decision making remains strong.

The following quote captures the general sentiment of comments received in this section:

'We hope we will become closer to being a 'partner' than just a group to be consulted'

2: Information and Knowledge

Likert items

The clearest trend in this section is for the three statements concerning group feeling towards the provision of information from the system (figure 2.1). The negative sentiment expressed here identifies the flow of information as a feature that warrants considerable attention. This corresponds to the generally negative response for the statement 'as a community, we understand the reasons behind decisions that have been made' (figure 2.2).

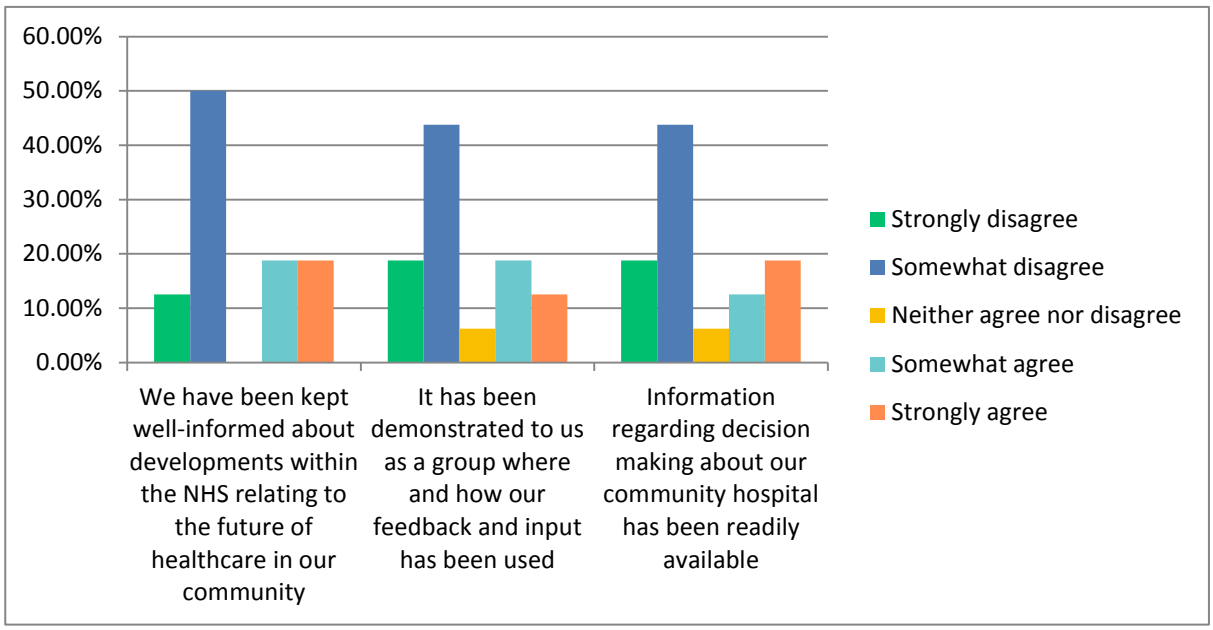

Figure 2.1

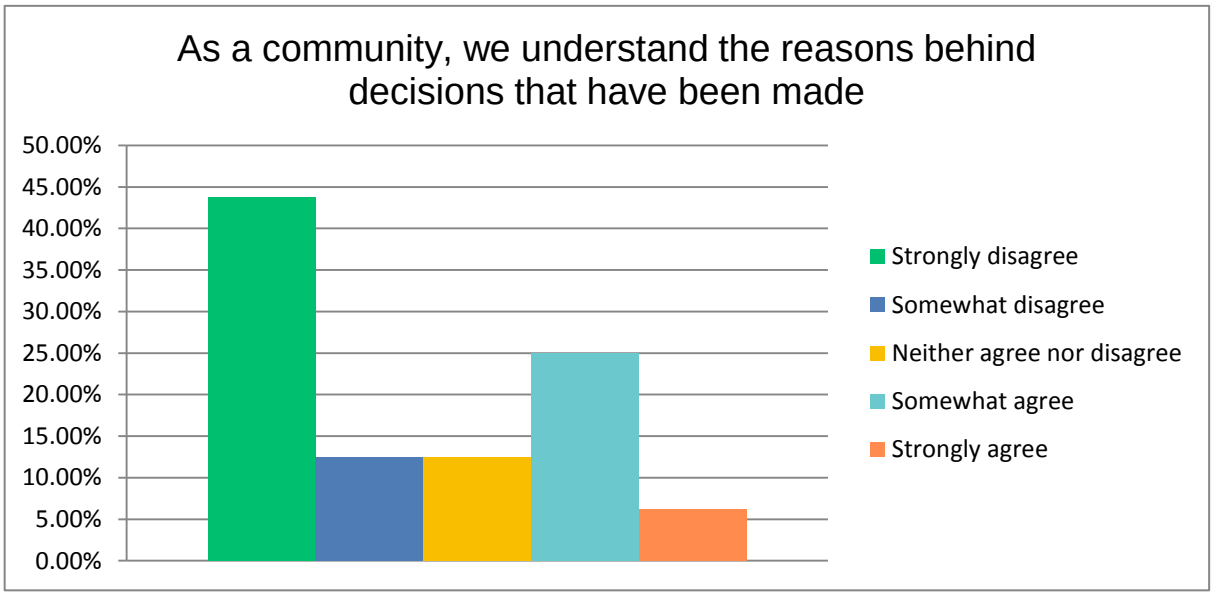

Figure 2.2

Encouragingly, responses to the statement ‘over time, our communications with the NHS have become more frequent’ were significantly positive (figure 2.3). This would suggest that, when viewing this in conjunction with other, less positive responses in this category (figures 2.1 & 2.2) that the situation is improving.

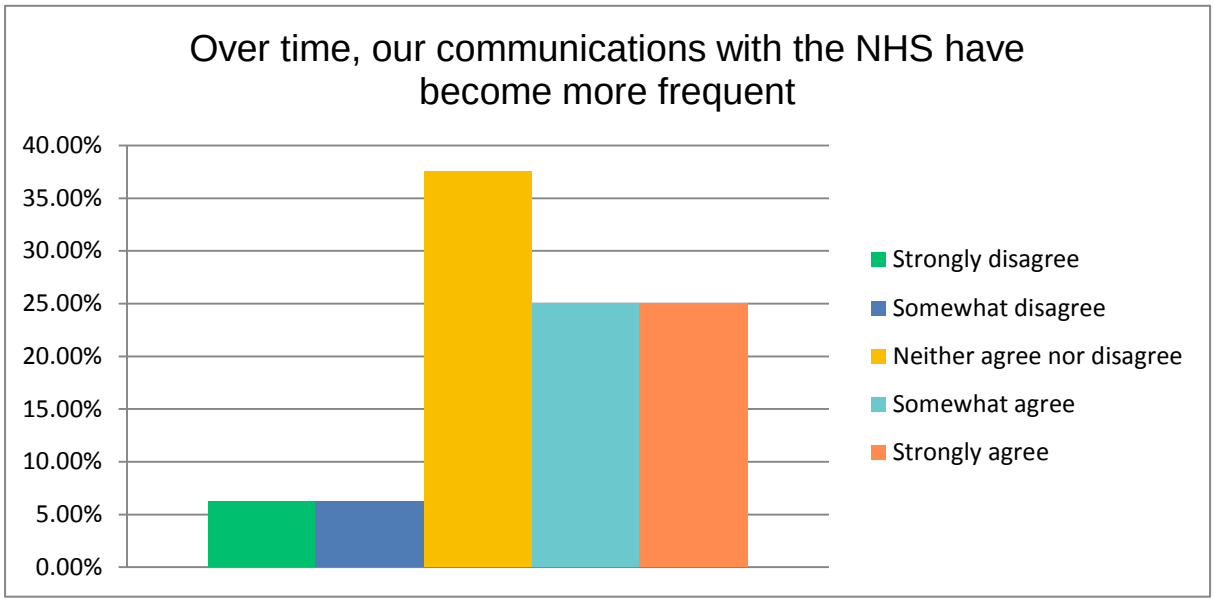

Figure 2.3

Other responses in this category do not exhibit strong positive or negative trends, but as a point of interest responses to the statement ‘the NHS understands our point of view’ are heavily polarised (figure 2.4).

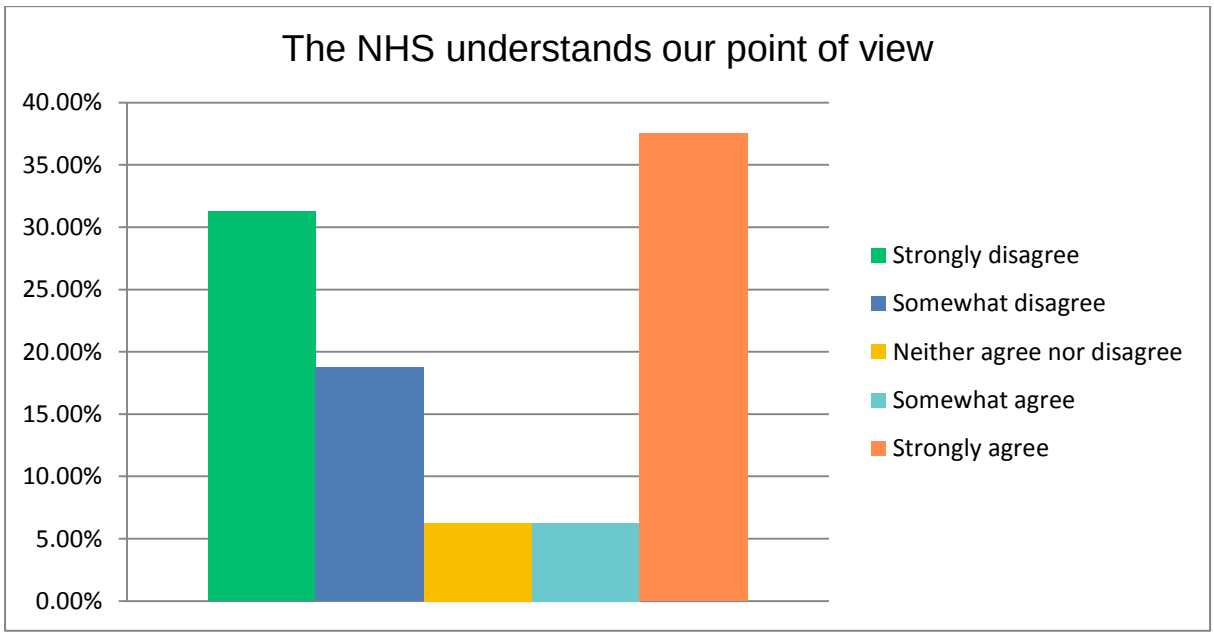

Figure 2.4

Open text fields

Comments received in this section were particularly revealing. Following on from the final item from the Likert items ('As a community, we understand the reasons behind decisions that have been made'), respondents were asked the question: 'Please could you tell us what you think the main reasons behind these decisions have been?'

Cost cutting was the most common response by far, with eight comments giving this as the primary reason. Three of these comments expressed the concern that cost cutting has taken priority over consideration of patient safety and health outcomes.

Other themes apparent in these comments were as follows

- That NHS decision makers lack understanding and are disconnected from the reality of the situation in rural areas, such as the challenges transport presents (4 comments)
- That this is a national issue (2 comments)
- That they are a consequence of the Success Regime (2 comments); these comments were strongly negative in sentiment, for example:
  'The success regime neither understood nor appreciated the role of community hospitals and made their recommendations accordingly. They then refused to acknowledge public opinion and were forced to defend their wholly unjustified report.'
- Staff shortages (2 comments)

Two comments in this section were positive in tone:

- Firstly that the main reason behind decisions has been:
  'Working more effectively to ensure the patient is at the hear of decisions about their care'
- Secondly that public consultation had:
  'promoted new initiatives which hopefully will improve health in Maryport as we now have assurances that the money saved will not be taken away!'

Part of one comment received in this section is not directly related to the question, but raises a very interesting point that warrants significant further attention:

'We're a rung below the ICC. This puts us in a very vulnerable position as we have no real influence or power; we tick the NHS community engagement boxes without being properly engaged, and the community will inevitably hold us responsible for any failure they perceive in relation to the hospital.'

3: Attitudes

As the sole aim of this section was to gather attitudinal data, it included no open text fields.

Firstly, this section contained the single Likert statement that generated a unanimously positive response: ‘involving communities in the 'co-production' of health service delivery is a good idea’ (figure 3.1)

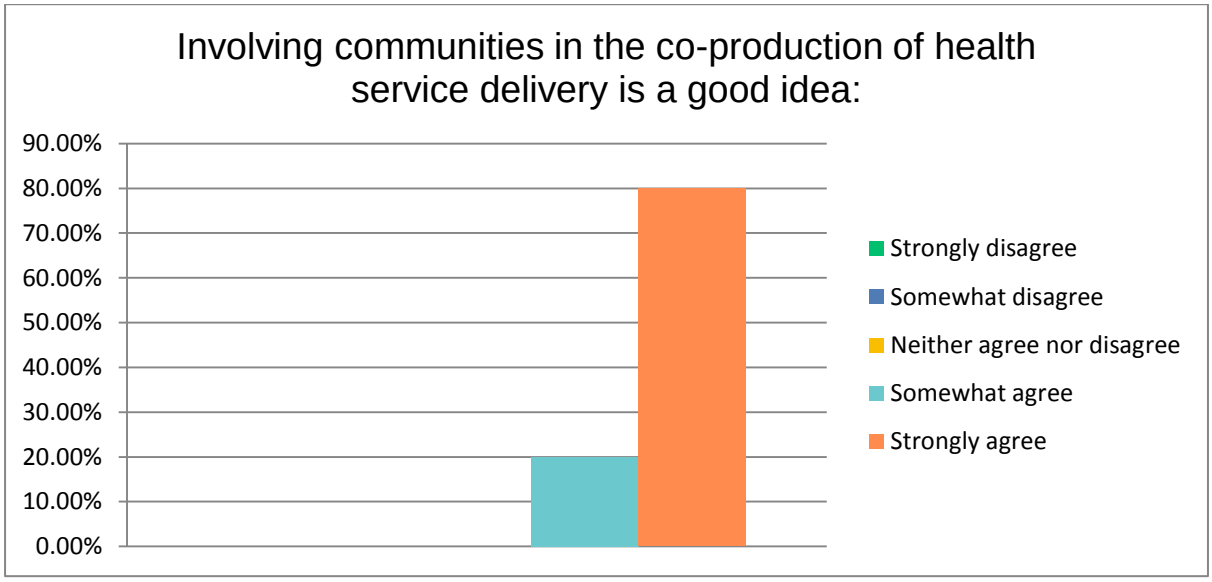

Figure 3.1

Another statement that generated a particularly strong response, perhaps unsurprisingly bearing in mind the comments received in the open text fields for section 2, was: ‘Changes to our community hospital are more about saving money than improving care’ (figure 3.2)

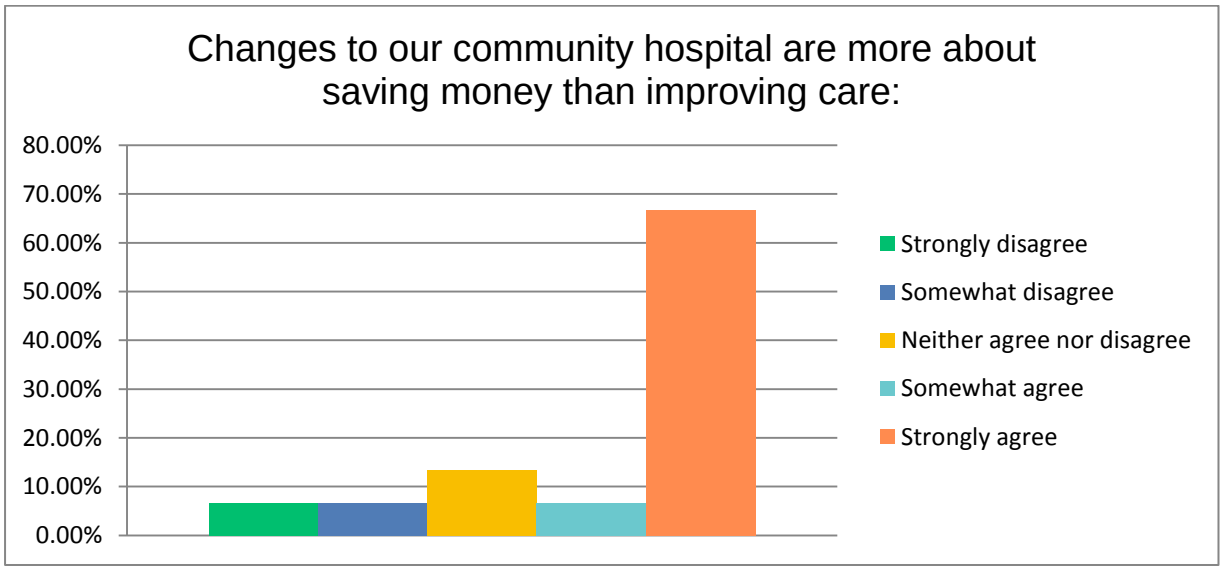

Figure 3.2

Respondents generally agree that the aims and perspective of the group are supported by the general public, and encouragingly, that co-production describes a meaningful change in how healthcare systems are organised (figure 3.3) .

Respondents generally disagree that the NHS is trying hard to involve community groups in decision making and that the NHS is listening to community groups, although in the case of the latter this is less pronounced (figure 3.4)

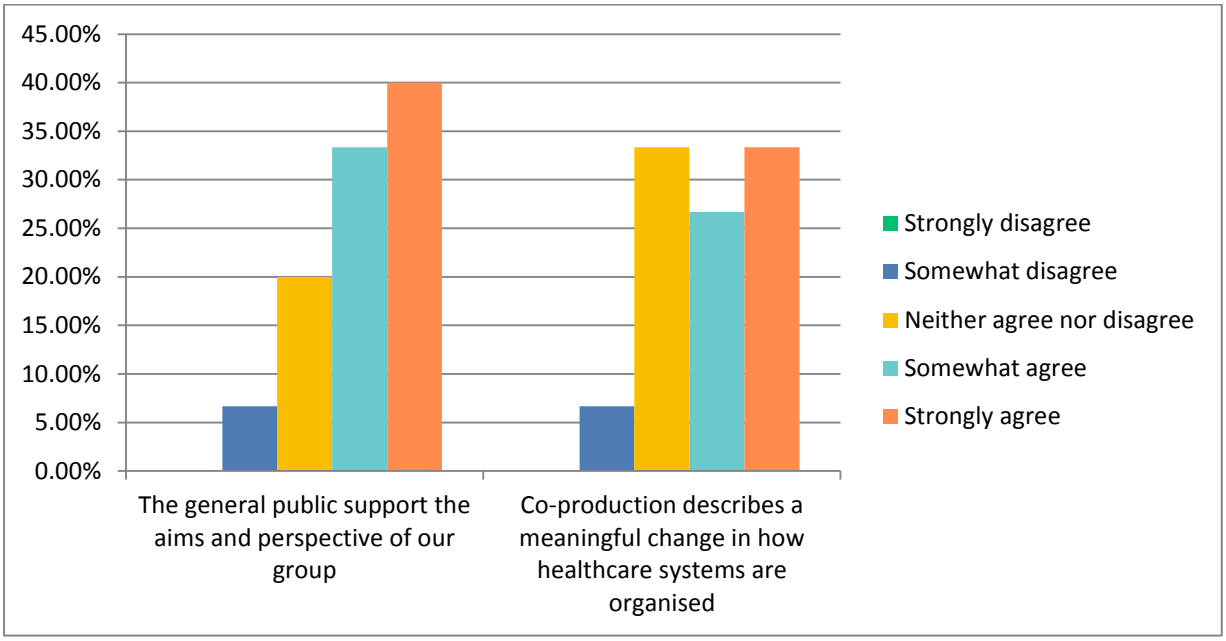

Figure 3.3

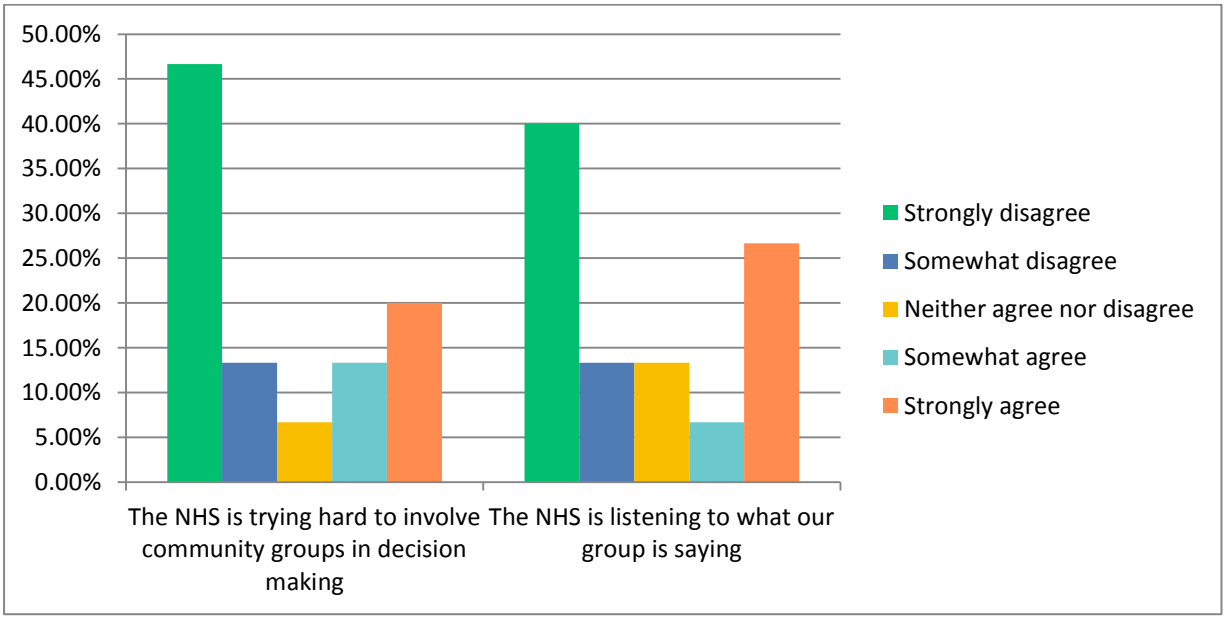

Figure 3.4

Two of the statements in this section elicited significantly polarised responses; firstly that NHS organisations have been open and transparent and secondly that the NHS understand the impact that changes to community hospitals will have. In the case of the first of these two points, strength of feeling was heavily weighted towards the negative response (figure 3.5).

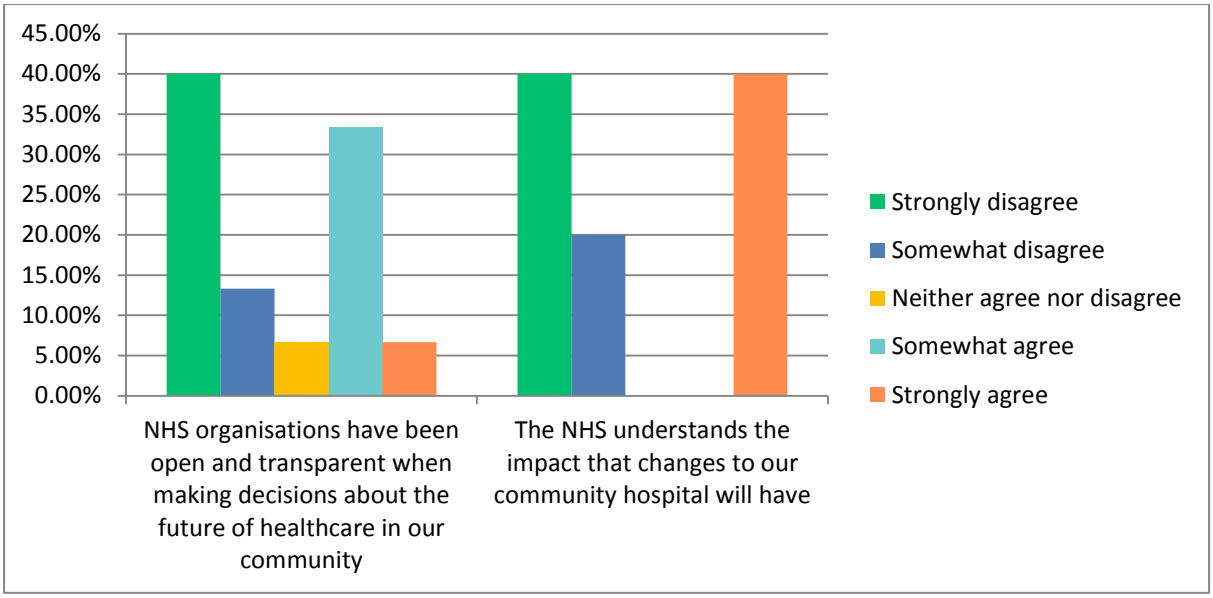

Figure 3.5

Finally, responses to two statements did not exhibit pronounced trends (figure 3.6).

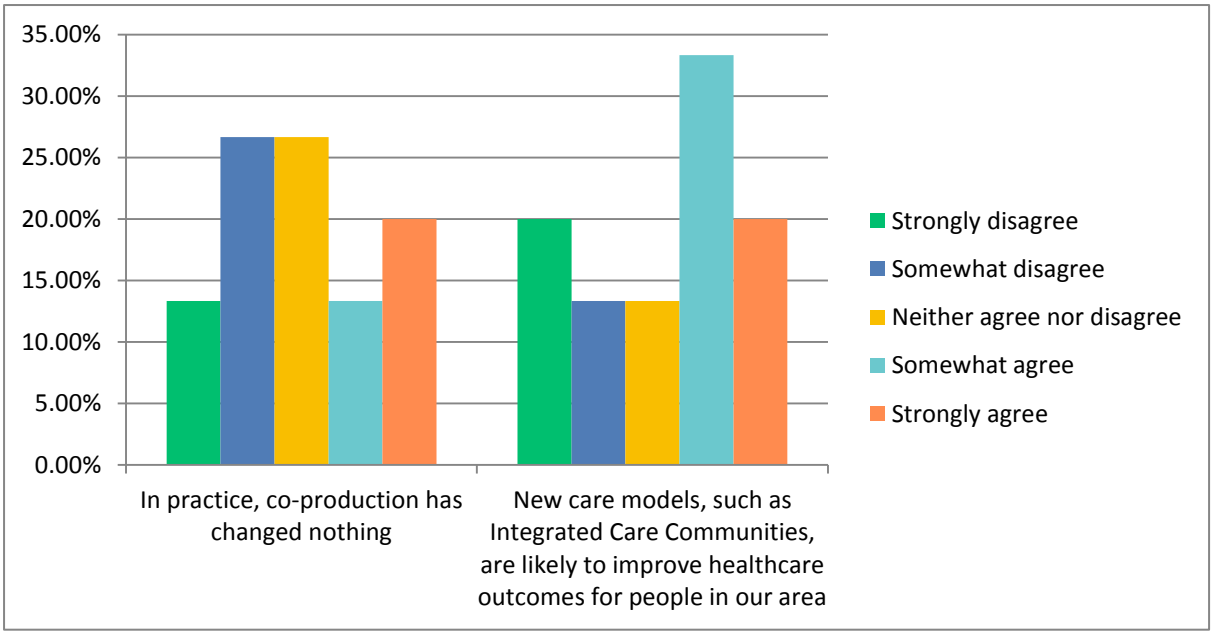

Figure 3.6

4: Outcomes

General satisfaction

Two of the items in this section were central to the first aim of the project, which was to assess whether respondents consider specific issues to remain unaddressed (figure 4.1). Closely connected to this was a statement concerning overall satisfaction with decisions that have been made (figure 4.2). Both of these items elicited a strong negative response.

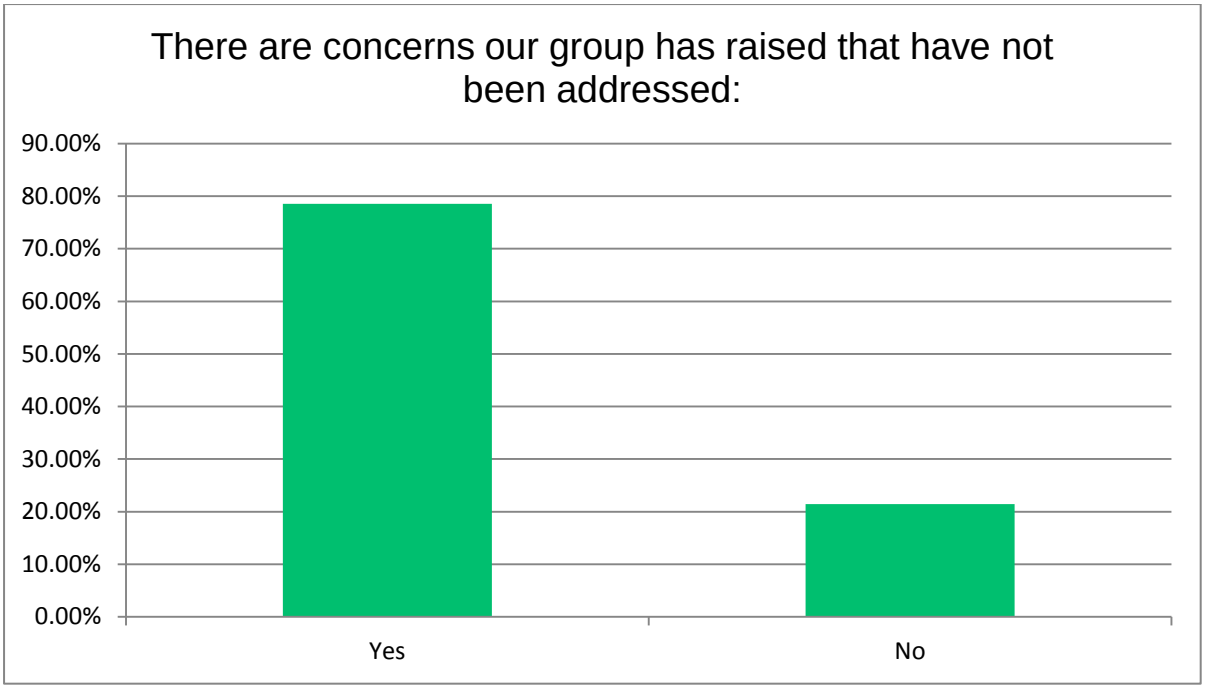

Figure 4.1

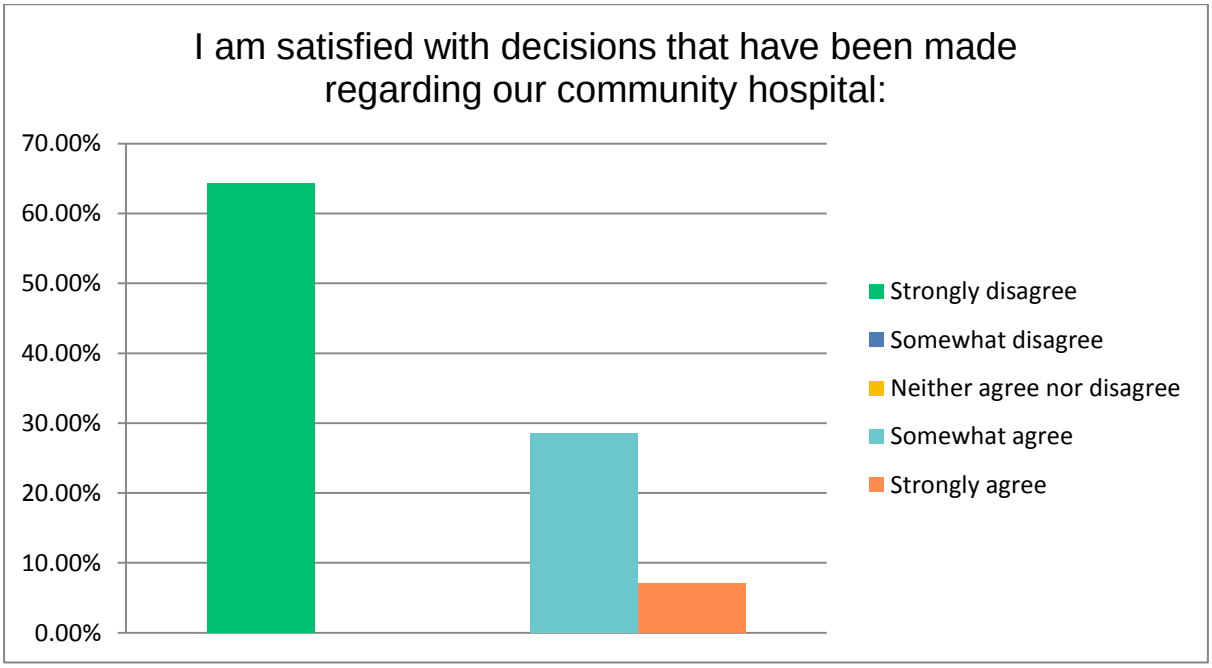

Figure 4.2

Co-production outcomes

Respondents indicated in general that their groups have become more involved in NHS decision making (figure 4.3). The other three Likert items in this section, which concerned perceived changes to expectations or understanding of the community groups, the NHS and individuals, displayed no clear trends (figure 4.4)

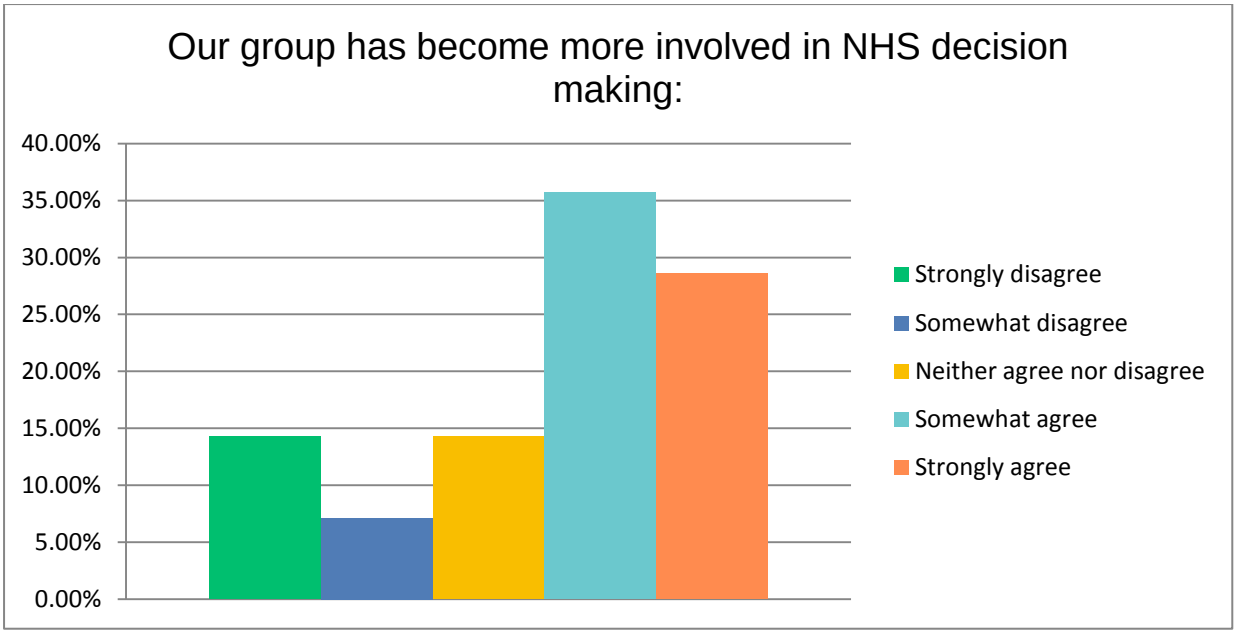

Figure 4.3

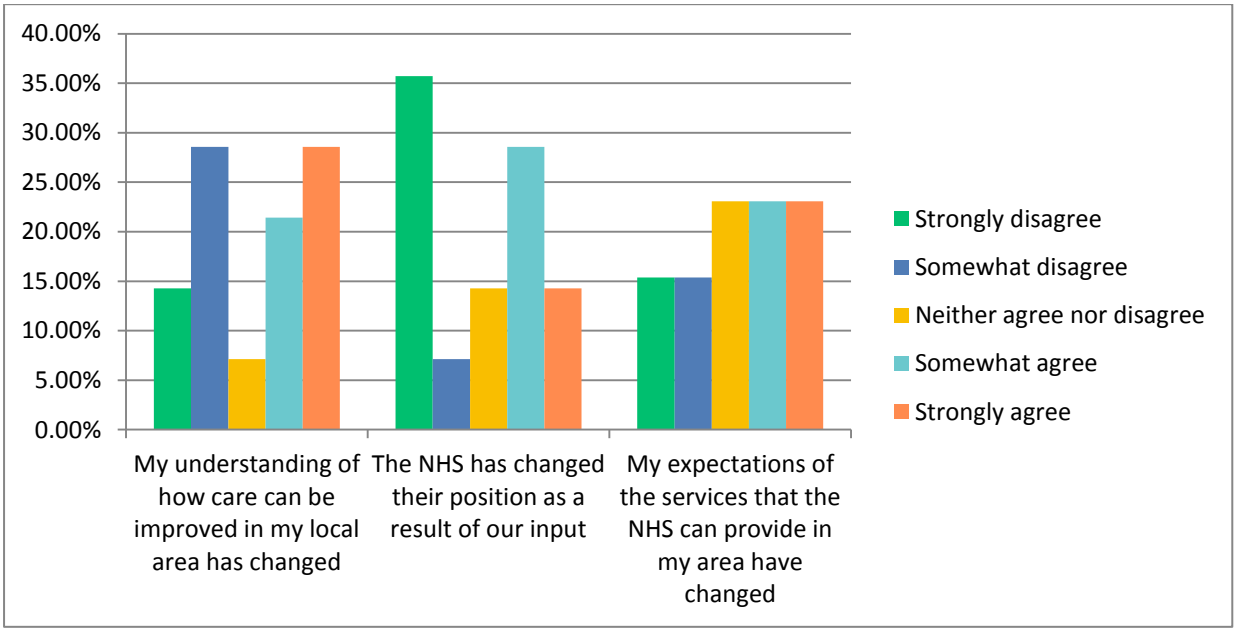

Figure 4.4

Open text one: Opinions and expectations

The first of these asked respondents in what way their opinions or expectations have changed regarding the future of healthcare in their community. The majority of responses to this question were strongly negative. These contained the following themes:

- General negativity, indicating either that opinions or expectations had remained negative, or had changed for the worse (7 comments)
- Concern about the potential for the community to be involved in decisions (1 comment)
- Concern over perceived inadequate staffing levels (1 comment)

Four comments were more positive in their outlook. Two of these were more general:

'We can do far more than we have been doing locally'

'ICCs should bring more localised care to this community'

The other two were more forward looking. One of these returned to the Success Regime, but expressed that the situation is improving:

> *'The 'Success' (an oxymoron) regime's recommendations demonstrated a total ignorance of the role of our Community Hospital... However with the active support from the trust senior management we now have a positive view of the future.'*

The other expressed optimism, but tempered this with suspicion:

> *'I'm a good deal more optimistic about what can be done by the nursing team in a community context; and possibly that telehealth developments will help if they're not all empty promises.'*

Open text two: Specific issues

The second of these asked about specific issues that respondents consider remain unaddressed. Responses to this question form the basis of the primary recommendation arising from this project. The following issues were identified:

- Loss of beds (3 comments)
- Transport to alternative facilities (3 comments)
- Palliative care (2 comments)
- The need for an improved flow of information and greater involvement in decision making (2 comments)
- The need for a new build care home in Alston (1 comment)
- The consequences for mental health issues and treatment (1 comment)

5: Engagement

Respondents self-rated the extent to which they have been involved in the community group from one to ten, with one being the least involved and ten being very heavily involved. The average figure given was 6.1 and the most common response was 10 (figure 5.1). The majority of respondents considered their involvement in the community groups to have remained roughly the same (figure 5.2).

Respondents generally intend to remain active members of their group. Responses to the final two items were mixed, with no pronounced positive or negative trend. These covered whether respondents felt that their involvement in the group had made a difference, and whether their involvement had been a positive experience (figure 5.3).

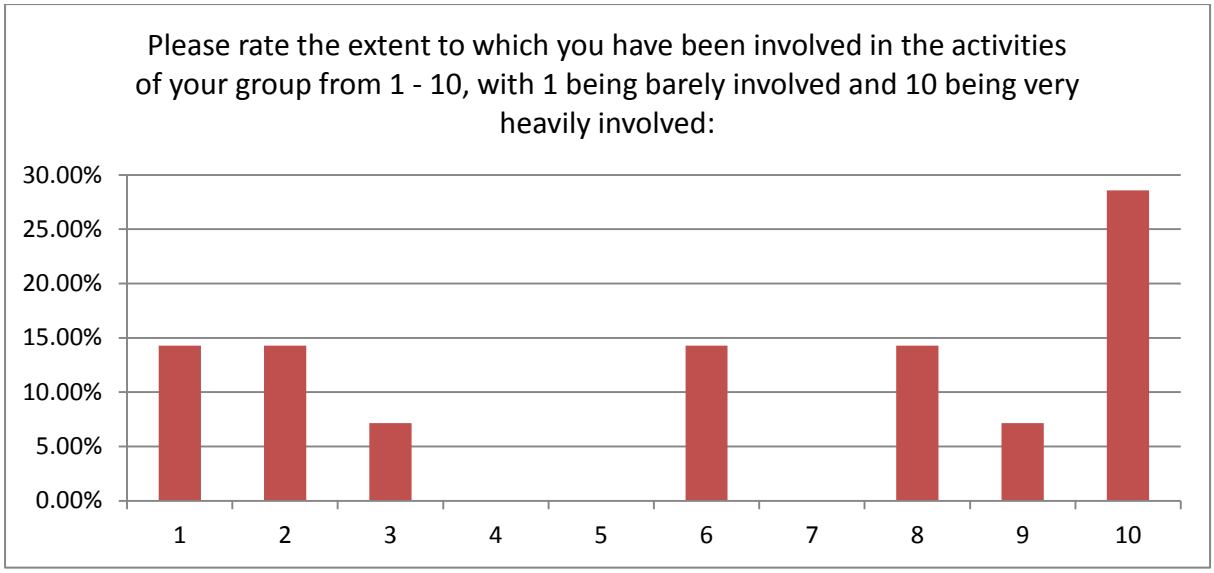

Figure 5.1

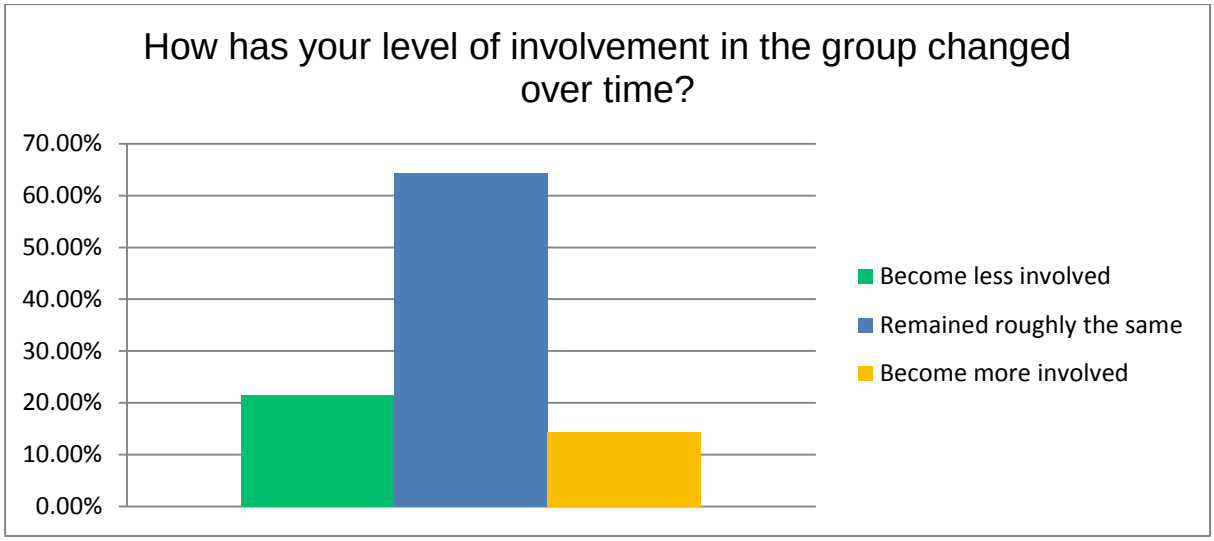

Figure 5.2

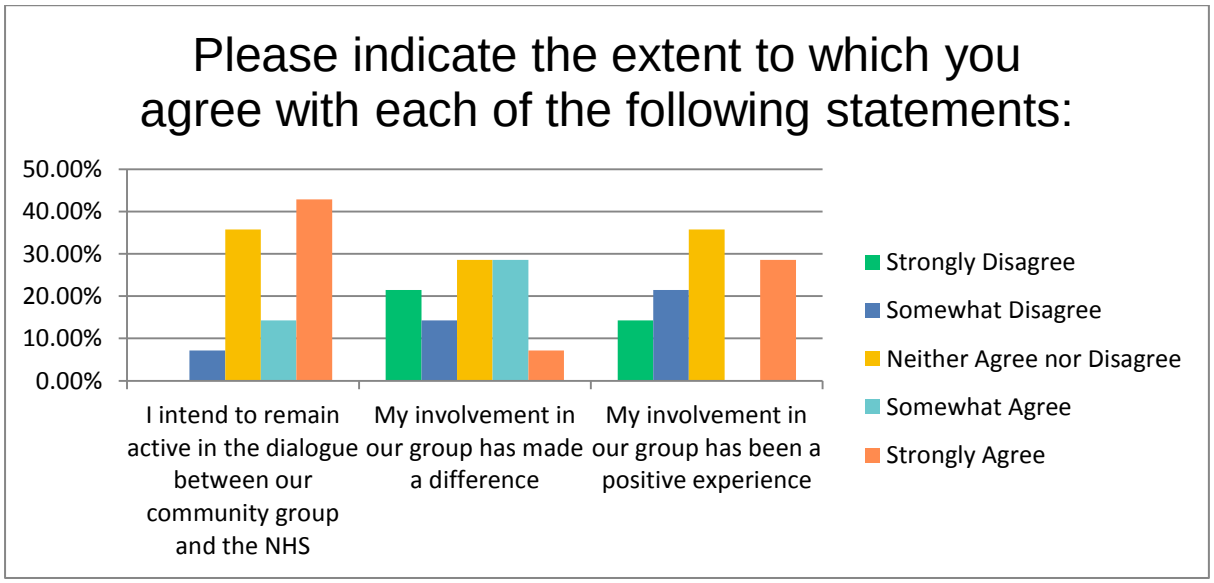

Figure 5.3

Focus Group Findings

This section summarises the discussions that took place during the focus groups in each location. The summaries aim to capture the primary topics of each conversation, which are presented under subheadings for clarity.

At this point it is worth reiterating the independence of HWC; the sole intention of this section is to relay the views and ideas of focus group participants. Views expressed herein are not to be considered those of Healthwatch Cumbria.

Alston

Communication

A number of features of the way that NHS organisations communicate with the Alliance were identified as problematic, and were viewed by participants to be significant barriers to improving the extent to which they trust the system.

Firstly, participants do not feel that they are provided with information that describes how their evidence or input has been used or considered, and whether it has resulted in any tangible outcomes. Where suggestions are rejected, they think there needs to be a clear explanation as to why and alternate proposals need to demonstrate clearly that the concerns of the community have been incorporated or accounted for.

Secondly, while the clarity of communication is generally considered to be good, participants stated that at times there seemed to be assumptions that the community or general public understand in depth how different services or organisations work. The Alston Alliance have a clear sense that they are the conduits for information between the NHS and the general public, so when documents are overly technical they are responsible for 'translating' these into a form that conveys the meaning to a lay audience.

Participants stated that the provision of key documents or agendas prior to meetings was unreliable and that frequently these were not available. They identified this as a serious problem, as they cannot maximise their contribution to meetings without the time and materials necessary to prepare thoroughly.

Transparency

Participants used this word frequently throughout the discussion. The point was made that 'information is power' and that the relationship between the NHS and the Alliance feels inherently unbalanced if information is not available. Where information is not provided, it breeds suspicion that it is being intentionally withheld to exclude the community from elements of decision making that they may disagree with.

It was acknowledged that this suspicion is likely to be unfounded and that unreliable provision of information is more likely to arise from insufficient resources being dedicated to ensure its timely delivery. This is probably not acknowledged in the same way by the general public, for whom the previous consultation conducted during the Success Regime generated widespread suspicion, which colours their perception of current community engagement.

Group Structure

Health Action and campaigning in Alston is very well established and has a core of dedicated, highly motivated individuals. There is also the League of Friends, which has existed for decades and had garnered the support of Penrith and Borders MP David Maclean during the initial consultations about the future of community hospitals in the county in 2006. The relatively recently formed Alston Alliance includes members who have been heavily involved for a long period, giving the group a stable foundation alongside the NHS and social care members.

Participants stated that one of the defining characteristics of the Alston Moor community is a strong community spirit. The Alliance has been able to draw on this extensive pool of social capital; both in terms of committed, motivated group members and also in garnering support from the general public. During the public consultation for the Success Regime, health activists were present in the centre of Alston every Saturday, meaning that they are well-established as the 'interface' between the system and the community.

The majority of the active health campaigners are (including some who have recently become) members of the Labour Party acting, in a sense, as a stable institutional foundation for the group. Participants felt that the existing agenda was of common interest to Labour Party members and that this, rather than partisan politicisation, was the reason for any crossover.

Participants expressed a sense that at times meetings of the Alston Alliance (including the NHS and CCC adult social care representatives) can be 'too nice' and that discussion tends to centre on points of consensus, meaning that points of contention are not necessarily subject to robust debate.

Participants feel that the powers and role of the Alliance group lack clarity and that establishing these more explicitly would help to maximise their potential to contribute.

The Success Regime

This was mentioned unprompted multiple times during the discussion. The general perception of it is extremely negative owing to, primarily, the severe lack of detail and basic factual accuracy in documents arising from it regarding Alston Moor. One participant summed up their feelings of despondency about the outcomes of the consultation period as such: 'why did we waste our time?' Participants drew a connection between this and the general air of suspicion prevalent within the broader community.

The Future

As health services in the area continue to develop over the coming years, in order for co-production to be successful, participants consider it essential to 'get the structure right' moving forwards. As telehealth and the future of Grisedale Croft become the focus of attention, participants consider there to be a large potential for the Alliance to make a valuable contribution. The deployment of digital technology presents an opportunity for rapid, tangible progress; community involvement in this, with a demonstrable impact on the outcome, would do much to build public trust.

Participants were optimistic about the prospects for community groups working in other locations or situations to share knowledge and experience to support one another. It was suggested that the means of identifying suitable members of the public to engage with could be improved. They thought that Pub landlords, posties or other individuals connecting with large numbers of members of the community would potentially have a far greater knowledge of local people than parish or district councillors.

Maintaining healthy relationships between the community and the system is dependant upon contingencies being developed for when things go wrong, as co-production can easily be derailed by misunderstandings. Mechanisms need to be in place at a systemic level to deal with complaints that the Alliance or the NHS may have about the conduct of the other. There is the potential for HWC to act as a facilitator, an 'early warning system' and interpreter in future discourse.

In general, participants expressed that they are tired, but cautiously optimistic about the future of healthcare and co-production in the Alston Moor area.

Maryport

Group Structure

Participants feel that the Alliance currently needs formal recognition, a mandate, terms of reference and some funding. While the Alliance had previously functioned well on an informal basis, at present, in the absence of a clearly defined structure, the Alliance is 'crumbling'. Disparate groups that had united to support the Save Our Beds campaign have reverted to following their own agendas.

The Alliance meet once every two months and various groups report back on what they are doing, but there is no overarching plan or strategy. The meetings are minuted however there is no action log produced from these. Participants consider there to have been a shift in the focus of attention; the Alliance now focus more on practical things they think they can influence.

This waning coherence is seen to be a product of the characteristics of the community as well as the NHS. On the one hand, there is a sense that 'the trusts don't understand co-production'. The Alliance do not know what the trust plans are, and there has been insufficient round-the-table planning. This leaves the Alliance floundering as it is unaware of how it can contribute. They think that 'the health system needs to give time and resources to the community'.

On the other hand, there are substantial differences of opinion within the community and the Alliance has struggled to accommodate these: 'there are some who do not want change to happen and will always present the negative perspective… it's a case of whose voice is loudest, positives or negatives!' This results in a feeling that it is up to the Alliance members who accept that change is inevitable, to 'forge ahead to achieve the vision'. A large part of this is the Alliance 'asking more questions to clarify what [they] either don't know about or understand'.

Relationships with Other Stakeholders

Participants think that in general, the wider community are not listening to or aware of the progress the system and the Alliance are making. This is because they are not informed about the 'bigger picture'. They suspect that this might be because 'the system thinks that they may not be ready to hear it'.

With regards to the NHS, participants stated that papers from the system are not always available prior to meetings and that this reduces their capacity to make a contribution. They feel that the NHS does not engage with them meaningfully and that they are not valued as a stakeholder group. They have the impression that they are used as part of a 'rubber stamping' exercise to satisfy the requirements of community engagement in order for the NHS to pursue its agenda without consulting the community. When comments are made by community representatives, they have the impression that the NHS perceives them to be antagonistic rather than constructive. Furthermore, they feel 'patronised' by the NHS; for example, after the last meeting with the CPFT, engagement took the form of a 'comments box', which demonstrates the lack of interest in local feeling.

The Success Regime

They view the Success Regime in a very negative light. During the initial consultation, the Alliance were able to collect 7,000 signatures on a petition, and this showed how energised the community was. Community spirit at this time was strong, but since the 'pathetic' consultation, they 'feel like giving up'. The Success Regime left the community feeling disempowered and marginalised.

The Future

Participants feel that they have no way of influencing NHS plans.

They see a potential role for HWC, believing that HWC involvement could help them achieve more, providing HWC could 'do any good'.

However, they did express considerable optimism about the future of healthcare in Maryport, with the community hospital acting as a 'hub' of services through its diversification. In particular, they are positive about the potential the hospital has to save large numbers of journeys to services that are currently only accessible elsewhere.

Wigton

Group Structure

The Alliance, initially the Solway Care Alliance, had ten members and two CPFT members present during its first five meetings. Following this, they opened meetings to the general public. At this time, thirty-three attended and 'chaos ensued', with everyone having their own agenda. Following this, the group was pared back to twelve members. In principle, if any member left the group, they were replaced by someone with similar interests to maintain the ideological composition of the Alliance. Participants think that this group size and structure is currently working well.

Community Engagement

Participants acknowledged that the contribution from the wider community has 'inevitably waned', owing to the practical complications of arranging meetings that accommodate the work-life schedules of potential attendees.

The Alliance is not fully representative of the wider community, as if it were to account for the full spectrum of opinions it would not be able to focus on achievable or practical goals. As such, those with a more negative point of view tend not to attend meetings or events.

Relationship with the NHS

In general, participants expressed satisfaction with their relationship with involved NHS organisations. They are provided support in the form of a chair, and legitimacy in the form of two high-level CPFT members attending Alliance meetings. Their perceived successes are in part attributable to personal contacts between Alliance members and those at the Trusts and with the local MP, with specific individuals being identified as being particularly helpful.

However, participants still expressed a sense that some decisions have been made by the NHS without the Alliance having all the information available. For example, estate assessment is ongoing, yet decisions have been made without their outcome being divulged.

Owing to the Alliance's strong relationship with the NHS, they feel that HWC are too late to facilitate in the discourse between the NHS and the community. They do however think HWC involvement would have been helpful earlier in the process.

The Future

Overall, participants consider Wigton to be a positive example of co-production. Having had a proposal identifying Inglewood Care Home as a suitable venue for overnight beds accepted, they can clearly distinguish the consequences of their input. They feel positive about their role in the ongoing development of ICCs.

Discussion

The considerable variation between the experiences and attitudes of community groups in Alston, Maryport and Wigton comprise a suite of highly informative case studies about co-production in action. This section aims to identify some of the key points for consideration and to unpick some of the lessons that can be learned, in order to strengthen co-production in the future, in the context of these community hospitals as well as elsewhere.

The Continuing Impact of the Success Regime

Firstly, it is essential to acknowledge the broad dissatisfaction apparent in the survey and focus group data regarding decisions made about the community hospitals in question. This seems heavily attached to the very strong negative feelings that are attached to the Success Regime. This was not mentioned by name in any of the survey items, briefs, or focus group materials, yet received considerable unprompted attention from respondents. In a sense, the Success Regime could be considered the elephant in the room; the bitter taste that it has left with many respondents is demonstrably a major factor in the general suspicion that is at the heart of general public and Alliance group perceptions of current co-production efforts.

Group Structure and Characteristics

There is substantial variation between the structures of each of the Alliances. Of the three, the Alliance in Alston has the longest heritage and the strongest core of heavily engaged individuals, who serve as its driving force. Over the years, members of community groups in Alston have become adept at making the most of the information made available to them by the system; this, in tandem with their strong presence in the wider community, has made them a stable and highly effective organisation. They have a very clear sense of the problems they face and, more importantly, of the means by which they could be resolved.

The Maryport Alliance is currently struggling; having lost momentum following the outcome of the Success Regime, they are not currently in possession of the status, information or membership that they need to be more effective. In contrast with Alston, the original driving force or core of the Maryport Alliance was drawn from a variety of other existing groups who, in the absence of perceivable impact on outcomes, have returned, despondent, to their original activities. This illustrates the need for a group with the primary focus of the community hospital itself. Whilst an ad-hoc Alliance comprising pre-existing community groups may be highly effective at garnering public support, as evidenced by the overwhelming response to the 'Save Our Beds' petition, this cannot be *expected* to persist, particularly in the face of adversity.

Conversely, the Wigton Alliance is currently thriving, owing firstly to the visible consequences of their activities, and secondly to the strong personal connections between core members and individuals within the NHS and other governance institutions within the area. They remain structured and committed, although the extent to which they are currently able to engage with and represent the full spectrum of community opinion is questionable.

Relationships with Existing Institutions

The questions raised by Wigton focus group participants themselves over the extent to which they are representative highlight one of the main challenges faced by co-production in general. Their relatively high level of satisfaction is completely at odds with recent media coverage highlighting the perspectives of disaffected members of the community[3] in

[3] The Cumberland News: *Councillor hits out at health chiefs over community hospital promises,* 26th October 2017

Wigton. In this instance, it would appear that members of the Wigton Alliance have 'forged ahead' with their vision, in the way that focus group participants from Maryport consider to be necessary in their situation, to keep things moving in their community.

The cost of this 'forging ahead' has been that the perspective of more sceptical or negative members of the community has been side-lined or marginalised, which, in theory, detracts from the overall community capacity to contribute to co-production. As the core individuals of the Wigton Alliance have become engaged more deeply with high level individuals within the NHS, they have arguably shifted from being more 'of the community' to being more 'of the system'.

In Alston, where community group members have become, to an extent, 'superimposed' upon the local Labour Party, it would seem there is a risk that the group may inevitably assume a more partisan political stance. At present, this relationship is more a product of the coincidental alignment of ideologies, so their agenda remains focussed on the community hospital. Bearing in mind the fact that, owing to the broad community support for the Alston Alliance, meetings can at times be 'too nice' or lacking in substantive debate, it would seem that there is a risk that an increased dependence on Labour Party membership could result in the Alliance drifting towards becoming more 'of the Labour Party' rather than 'of the community'. This could result in the de facto marginalisation of alternate viewpoints in a similar way to that which has superseded the Wigton Alliance's closer relationship with the NHS.

Information and Co-production

The findings of this work show that the prevalence and exchange of information between the NHS and community stakeholders is a critical variable in the co-production process. Where information is scarce, community groups tend to become suspicious that this is a result of wilful opacity on the part of the NHS, which is not conducive to a healthy collaborative process. On the other hand, where information is reliably available, community groups feel empowered, engaged and valued.

Co-production needs to flow both ways; there is a responsibility for community groups to acknowledge that if their original wishes are impossible that they must be flexible too. Our findings suggest that this can easily happen when conditions are right; specifically, when comprehensive information is available regarding the underlying context in which decisions are made, the nature of decision making processes and the manner in which community ideas have been taken into account.

In the context of community hospitals, the Alliances can be seen to serve as the interface between the system and the general public. By providing clear information, the NHS can assist the Alliance groups as the conduits for this information; the need for Alliance groups to reform or 'translate' official documentation into lay terms presents another potential barrier to successful co-production. Where Alliances are struggling to accommodate the more sceptical or negative members of the community, it is acknowledged that the general public are not aware of the bigger picture.

Survey responses show that, for the most part, respondents currently do not consider the provision of information to be adequate, which correlates with the negative response to

the statement that ‘the NHS is trying hard to involve community groups in decision making’.

Conclusion

The co-production process in relation to the community hospitals in Alston, Maryport and Wigton is relatively well advanced in comparison with that surrounding many of the changes to health and care services underway elsewhere in the county. It is therefore the case that lessons learned from the experiences of those involved in co-production in Alston, Maryport and Wigton will be of considerable value as practical examples of co-production in action.

However, some aspects of co-production in Alston, Maryport and Wigton are less advanced and an effort must be made to resolve these to produce a more detailed template so that community engagement can start on a stronger footing elsewhere.

Commitment to the principle of co-production remains strong and as events move forwards, increased understanding of the factors responsible for its success or failure improve its efficacy.

HWC welcomes the opportunity to embed some of this learning and draw on best practice elsewhere to enhance the co-production project commissioned by the CCG which will result in further recommendations and a toolkit of materials to support co-production.

Recommendations

- Specific issues revealed in the survey data that community groups perceive to remain unaddressed must be the subject of further discussion in the near future.
- Health and care organisations need to be actively involved in the co-production training that HWC is developing with Cumbria Learning and Improvement Collaborative (CLIC) so that the learning from their perspective can be incorporated in that project.
  This could be supported by producing a short paper on their experiences of working with each of the groups, including their experience of working with each of the groups;
  - Wigton, i) established group with backing of MP and apparently high level members of staff within the NHS, firm commitments for support from these; ii) contradictory information coming from Wigton.
  - Maryport: dialogue appears to be less well developed.
  - Alston: working with a well organised, highly active, dedicated community
- Early, transparent and comprehensive information for each change being coproduced is essential prior to any co-production project. This should include information about cost, quality, recruitment.
- Co-production meetings should be jointly planned and designed to ensure that everyone is listened to – agenda and supporting material should be available to all participants 5 days in advance to support equity of participation

- Provide clarity about the exact scope of the co-production, what decisions can be jointly taken, and when decisions are not the focus clarify exactly how discussions with inform future decisions
- Effective co-production requires significant resource provision - the HWC/CLIC project will help to identify the type and extent of resource required
- HWC to provide ongoing mediation and act as an advocate of the co-production process
- Future research to be undertaken to gauge general public understanding of the rationale and process of co-production

Acknowledgements

Healthwatch Cumbria would like to thank everyone who took the time to participate in the survey and focus groups; the date from which has provided the evidence base for this report.

Report Author

Andrew Gibson
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Healthwatch Cumbria

Appendix 1: Community Hospital Groups Survey & Brief[4]

healthwatch Cumbria Community Hospital Groups Survey

Introduction

Healthwatch Cumbria (HWC) acts as the independent representative of the public within the health and social care system in Cumbria. We listen to people's experiences of health and social care services and relay these to decision makers to inform the delivery and improvement of these services.

HWC would like to invite you to participate in a project about Alston, Maryport and Wigton community hospitals and the local interest groups that have been involved in the discourse surrounding their future.

The emergence of these groups is a significant development in healthcare governance in Cumbria. The experiences of those who have been involved in discussions relating to these community hospitals can offer valuable lessons to community groups and decision makers working to develop healthcare services elsewhere in the county.

The aims of the project are as follows:

1) To assess whether community groups' understanding of the current situation matches that of the NHS organisations involved in shaping the future of these community hospitals.

2) To reflect more generally on the relationship between community hospital groups and the involved NHS organisations as examples of the collaborative or 'co-production' design of services.

Findings will be collated and published in a short report in early 2018. HWC will request a formal response from the Clinical Comissioning Group (CCG) and the Cumbria Partnership Foundation Trust (CPFT). HWC will aim to act as a facilitator in future discussions geared up towards resolving any differences in opinion that are revealed by the project.

The survey should take around five minutes to complete. We would greatly appreciate your input.

The closing date for this survey is the 3rd of January 2018 at 5 p.m.

This survey is being undertaken by Healthwatch Cumbria. All information supplied will be held by Healthwatch Cumbria and will remain secure and confidential. Any information provided will be used only for the purposes of this research and any subsequent follow-on projects, and will not be passed onto any third parties or used for marketing purposes in accordance with the Data Protection Act 1998.

[4] Blank spaces and misaligned objects are the results of quirks in the software used to import the survey into this document.

Section 1: About your group

Please note that throughout the survey we use the generic term 'group' to refer to Community Hospital Alliances, Leagues of Friends and other interest groups in order to keep the wording clear.

1. Our group is well organised:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Please select one:	○	○	○	○	○

2. Over time, the level of organisation in our group has:

	Decreased significantly	Decreased slightly	Remained roughly the same	Increased slightly	Increased significantly
Please select one:	○	○	○	○	○

3. Over time, the number of people participating has:

	Decreased significantly	Decreased slightly	Remained roughly the same	Increased slightly	Increased significantly
Please select one:	○	○	○	○	○

4. Please rate the frequency with which the group currently communicates via:

	Never	Rarely (less than once a month)	Sometimes (a few times a month)	Regularly (once or more a week)	Often (most days)	Very often (more than a day)
By post	○	○	○	○	○	○
Email	○	○	○	○	○	○
Facebook	○	○	○	○	○	○
In person	○	○	○	○	○	○
Telephone	○	○	○	○	○	○

Other (please specify)

5. Please indicate whether the group's usage of these means of communication has increased or decreased over time:

	Used less frequently	Roughly the same	Used more frequently	N/A
By post	◯	◯	◯	◯
Email	◯	◯	◯	
Facebook	◯	◯	◯	◯
In person	◯	◯	◯	
Telephone	◯	◯	◯	◯

Other (please specify)

6. Please indicate the extent to which you agree with the following statements:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Members of our group share a vision for the future of healthcare in our community	◯	◯	◯	◯	◯
The NHS supports our group to ensure that our input into decision making is maximised	◯	◯	◯	◯	◯
Our group has the resources it needs to be effective	◯	◯	◯	◯	◯
Our group can provide valuable input into decision making around healthcare provision in our community	◯	◯	◯		◯

7. What would help your group to work more effectively?

Section 2: Information and Knowledge

This section is about the exchange of information between community hospital groups and NHS organisations, and the extent to which groups feel informed about developments regarding healthcare services in their area.

8. Please indicate the extent to which you agree with the following statements:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
As a group, we have strong links with contacts in the NHS	○	○	○	○	○
Over time, our communications with the NHS have become more frequent	○	○	○	○	○
We have been kept well-informed about developments within the NHS relating to the future of healthcare in our community	○	○	○	○	○
It has been demonstrated to us as a group where and how our feedback and input has been used	○	○	○	○	○
Information regarding decision making about our community hospital has been readily available	○	○	○	○	○
Information regarding decision making about our community hospital has been presented clearly and jargon free	○	○	○	○	○
The general public are aware of the potential consequences of changes to our community hospital and the care model that it is part of	○	○	○	○	○

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I am aware of the time- frame in which decisions need to be made about the future of our community hospital	◯	◯	◯	◯	◯
The NHS understands our point of view	◯	◯	◯	◯	◯
As a community, we understand the reasons behind decisions that have been made	◯	◯	◯	◯	◯

9. Please could you tell us what you think the main reasons behind these decisions have been:

Section 3: Attitudes

This section aims to gauge the strength and nature of feelings towards different elements of the governance of community hospitals.

10. Please indicate the extent to which you agree with the following statements:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
NHS organisations have been open and transparent when making decisions about the future of healthcare in our community	○	○	○	○	○
Involving communities in the 'co-production' of health service delivery is a good idea	○	○	○	○	○
The general public support the aims and perspective of our group	○	○	○	○	○
Co-production describes a meaningful change in how healthcare systems are organised	○	○	○	○	○
The NHS understands the impact that changes to our community hospital will have	○	○	○	○	○
In practice, co-production has changed nothing	○	○	○	○	○
The NHS is trying hard to involve community groups in decision making	○	○	○	○	○
New care models, such as Integrated Care Communities, are likely to improve healthcare outcomes for people in our area	○	○	○	○	○
The NHS is listening to what our group is saying	○	○	○	○	○
Changes to our community hospital are more about saving money than improving care	○	○	○	○	○

Section 4: Outcomes

11. Please indicate the extent to which you agree with the following statements:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I am satisfied with decisions that have been made regarding our community hospital	◯	◯	◯	◯	◯
Our group has become more involved in NHS decision making	◯	◯	◯	◯	◯
My understanding of how care can be improved in my local area has changed	◯	◯	◯	◯	◯
The NHS has changed their position as a result of our input	◯	◯	◯	◯	◯
My expectations of the services that the NHS can provide in my area have changed	◯	◯	◯	◯	◯

12. If you feel that your opinions or expectations have changed regarding the future of healthcare in your community, please could you tell us in what way?

13. There are concerns our group has raised that have not been addressed

◯ Yes

◯ No

14. If yes, could you tell us what these are?

Section 5: Engagement

15. Please rate the extent to which you have been involved in the activities of your group from 1 - 10, with 1 being barely involved and 10 being very heavily involved:

	1	2	3	4	5	6	7	8	9	10
Please select one:	○	○	○	○	○	○	○	○	○	○

16. How has your level of involvement in the group changed over time?

	Become less involved	Remained roughly the same	Become more involved
Please select one:	○	○	○

17. Please indicate the extent to which you agree with each of the following statements:

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
I intend to remain active in the dialogue between our community group and the NHS	○	○	○	○	○
My involvement in our group has made a difference	○	○	○	○	○
My involvement in our group has been a positive experience	○	○	○	○	○

Thank you

Thank you for taking the time to participate in this survey.

For any further information or queries relating to this work, please email us at info@healthwatchcumbria.co.uk

or call us on 01900 607208

Best wishes,
The Healthwatch Cumbria team

Appendix 2: Focus Group Discussion Points

Focus Group Themes & Discussion Points

1) About the community group
   - 1.1 A bit about their history as a group
   - **1.2 How the group has changed over time: numbers of people involved, extent to which people are involved**
   - 1.3 How dependent are the groups on the input of key individuals
   - 1.4 Communication between group members
   - **1.5 Diversity of opinions / perspectives represented within the membership – are these unanimous or are there people with alternate visions for how the situation can progress?**

2) Information and knowledge
   - **2.1 Exchange of information between the group and the NHS – what has this involved and has it been satisfactory?**
   - 2.2 How well informed do people feel:
   - 2.3 As a group
   - 2.4 As individuals
   - 2.5 Are the public well informed?
   - 2.6 Does coverage in the press reflect the reality?

3) Attitudes
   - **3.1 How optimistic are people that a satisfactory outcome can be achieved? / Are people cynical?**
   - **3.2 Perception of the NHS organisations involved**
   - **3.3 What does co-production mean to people?**

4) Outcomes

   This section deals with more specific issues:
   - 4.1 How do people feel about decisions that have been made?
   - **4.2 What issues remain unaddressed?**
   - 4.3 How have the groups' relationships with contacts in the NHS developed?
   - **4.4 Have the perspectives of community groups altered at all throughout the process?**

5) Engagement
   - **5.1 Do people feel listened to?**
   - 5.2 Has fatigue set i?
   - **5.3 Are people committed to remaining engaged with the process?**
   - 5.4 How do they thing an organisation like Healthwatch could contribute to the process?

Appendix 3: Focus Group Briefing

Healthwatch Cumbria (HWC) acts as the independent representative of the public within the health and social care system in Cumbria. We listen to people's experiences of health and social care services and relay these to decision makers to inform the delivery and improvement of these services.

HWC would like to invite you to participate in a project about Alston, Maryport and Wigton community hospitals and the local interest groups that have been involved in the discourse surrounding their future. In addition to surveys that we have circulated amongst members of these groups, we are holding focus groups for members of each of the community groups.

The purposes of the focus groups are:

i) To hold more in-depth discussions based loosely around the themes that the survey covers and give members an opportunity to voice any suggestions, concerns or grievances that they may have
ii) To introduce Healthwatch Cumbria to the groups involved and discuss the ways in which we can work together

Findings from the focus groups will be collated with those from the survey and published in a short report in early 2018. HWC will request a formal response from the relevant NHS organisations. HWC will aim to act as a facilitator in future discussions geared up towards resolving any differences in opinion that are revealed by the project.

The experiences of community groups that have been involved in discussions relating to the future of these community hospitals can offer valuable lessons to community groups and decision makers working to develop healthcare services elsewhere in the county. We hope to strengthen the co-production process so that it may be employed at the core of the continuing development of healthcare services in local communities across the county.

We would greatly appreciate your participation in these discussions.

Best wishes,

All at Healthwatch Cumbria