

## Response to the Deciding Together - adult mental health consultation

This response is in two parts. The first will focus on the engagement and involvement of service users and the public leading up to and during the consultation. The second part will give a response to the consultation and the options presented itself.

### Engagement and involvement

Newcastle Gateshead Clinical Commissioning Group (CCG) set up an advisory group to support and advise on the engagement and consultation. This group consisted of statutory and voluntary and community sector (VCS) partners as well as both Healthwatch Newcastle and Healthwatch Gateshead representatives. Healthwatch Newcastle acknowledges the challenges that the CCG has faced in getting regular representation from Gateshead-based organisations at the advisory group meetings. There has also been intermittent attendance from carers' organisations, particularly those based in Gateshead. We believe this has mainly been due to organisational capacity on behalf of the VCS organisations and this concern was frequently raised by all members of the advisory group and actions were taken to try to address this.

The pre-consultation engagement period started in the summer of 2014. Initially, it was conducted around traditional lines of public meetings and there were a range of venues and times for these events. However, the content of the events didn't support service user and public engagement. The language used to describe services was often confusing and required a high level of service structure knowledge to be able to input meaningfully. This problem was highlighted to the CCG in September 2015.

The CCG has taken steps to adjust its methods of engagement, directly acting on suggestions made by members of the advisory group. For example, the participatory budgeting event was developed following a suggestion by an advisory group member and additional feedback sessions were planned to address concerns raised in the group. The advisory group reviewed engagement materials and the consultation documentation prior to publication.

The quick turnaround time required for much of the engagement materials did cause concern for advisory group members. This could be as little as 24 hours and put unachievable demands on people's time. However, there is evidence that lessons were learned between the pre-consultation engagement phase and the consultation. There was a clear plan of timescales so that people could plan time to review documentation. The timescales slipped but generally, more time was available for the consultation than for the engagement phase.

We believe that there have been some very good examples of engagement during the pre-engagement and the consultation:

- Focus groups - VCS organisations have been encouraged to hold focus groups with their client group. There is a clear demonstration of learning between the engagement and consultation phases with the VCS organisation being invited to help develop the focus group tools and material and training being made available to support their use. The CCG also moved from offering a flat £100 fee to cover the expenses etc. of running the focus groups to an agreement to cover reasonable expenses. This offer was taken up by a number of organisations, particularly during the consultation.
- One to one interviews - working with Northumbria University, the CCG supported peer interviewers to conduct one to one interviews with service users and carers of service users.

- On-street survey - the CCG undertook on-street surveys to capture the general public's attitudes to the general principles of Deciding Together and to look at the issue of stigma associated with mental health services and service users.
- Participatory budgeting - the participatory budgeting events allowed a wide range of people and organisations to consider the various elements of the adult mental health services and to give an indication of priorities. This was not only a useful exercise to gain views and approaches to the issues but also gave participants unused to the world of NHS commissioning an insight into the complexity of the decisions that are taken.

There have also been a number of challenges during the consultation:

- **Language:** The issues related to the language used throughout the engagement and consultation have continued to an extent (multi-agency initial response system, community wellbeing hub, community based residential rehabilitation). This has been moderated to a large extent but we would like to have seen this go further to help people to understand exactly what was being discussed.
- **Older people's care:** There has been little overt discussion about the options for older people's care in Newcastle. This may have been complicated by the fact that this issue related only to Newcastle and not across the whole CCG area. We will be interested to see if any of the focus groups or one to one interviews are with people with dementia or their carers.
- **Representation from Gateshead:** The CCG has failed to gain an equal level of VCS engagement across Newcastle and Gateshead. We acknowledge that repeated efforts have been made to engage with organisations such as Gateshead Crossroads and other carers' organisations as well as with Gateshead Voluntary Organisation Council (GVOC) but these have not been successful. We also acknowledge that, with support from advisory group members and from VOLSAG mental health network in particular, the CCG has run a focus group with Gateshead based VCS organisations. We're unsure if more could have been done to address this concern and are reasonably confident that service users in Gateshead have had the opportunity to comment on the consultation.
- **Delay to the travel and transport report:** The CCG commissioned an independent travel and transport report, the results of which have not been available during the consultation. This has been a significant gap and we have asked the CCG to make it clear that further discussion of the options, in the light of the report, will be possible during the feedback phase. We have also asked that the CCG share Northumberland, Tyne and Wear NHS Foundation Trust's (NTW) transport policy along with other key information, online prior to the consultation closure so that people can consider this during their responses.
- **Detail regarding community based services:** There has been a lack of detail about the proposed community based services. We know that the CCG is keen to develop these in partnership with service users, carers and other key stakeholders following the decision on future model of care. We also know that some of the factors affecting which community based services are possible are dependent on the level of funding released by the future model of care chosen. However, the lack of detail has added a degree of uncertainty into the consultation that has left some feeling that it is difficult to give informed feedback.

On the whole Healthwatch Newcastle feel that the pre-engagement and consultation have been very well run. The CCG has been responsive to suggestions for change and improvement and has been eager to keep everyone involved. The advisory group has not been a 'cosy', easy group by any means and we feel that partners have given significant challenge to the CCG and to each other. Other than the areas

highlighted above, we find it difficult to identify anything more that could or should have been done to make it more comprehensive.

### Consultation scenario response

Healthwatch Newcastle's response to the scenarios and consultation is informed by the views it has heard throughout the pre-engagement and consultation and by general engagement with service users and the public undertaken as part of our usual business. We understand that the options presented to the public for consultation were only those that were affordable and credible and had been distilled from a wide range of options developed following the pre-engagement.

The following themes have been evident throughout the Deciding Together process and are mirrored in the ad hoc comments we have received:

- **Community care:** People are keen to see care delivered quickly and conveniently to stop their illness escalating. They want to feel confident that the appropriate help will be there for them when it is needed. Many have said how important it is that services delivered in the community are improved so that they can meet these needs. People want good quality community services in Newcastle and in Gateshead that support them for as long as required and are easy to re-access should they become ill again.
- **Proximity:** There is a great deal of anxiety about the loss of local inpatient beds. People have said that, in contrast to many patients receiving treatment for physical ill health, patients are often in hospital for a long time and therefore the impact of regular visiting on relatives, carers and friends is greater. Receiving visitors and maintaining contact with life outside of the hospitals is seen as essential to people's recovery.

Concern has also been expressed about distance and difference between a person's home and the inpatient facility and the impact on home visits etc. Service users from Newcastle have mentioned that both Morpeth and Sunderland are very different environments to Newcastle and will therefore feel unfamiliar and, perhaps, intimidating when they are able to go out of the inpatient unit for short periods. Others are concerned about the amount of time they would have to travel to return home for short visits.

- **Capacity:** People have questioned the overall reduction of beds and expressed concerns that this will lead to beds not being available when required and patients being sent further away for inpatient care. We note that the CCG has repeatedly spoken about the need to 'double-run' old services alongside new for a period of time to make sure that beds have not been reduced too far. We also acknowledge that an outcome from improved community services should be that there is a lower demand for inpatient treatment. We stress, however, that in some cases inpatient treatment will be appropriate, no matter how efficient and comprehensive the community services are.
- **Travel:** Many have expressed concerns about the difficulty and cost of travelling to Hopewood Park in Sunderland and St George's Park in Morpeth. Many service users, relatives, carers and friends in Newcastle rely on public transport. People have spoken about the complicated journeys, concluding with long walks, which will be required to visit these sites. We are pleased that NTW has committed to ensuring that travel costs for service users and carers have been met, however, we would like to better understand that definition of a carer. We would also like to know if this offer will extend to other family members and/or close friends that will be key to maintaining the wellbeing of patients whilst an inpatient. We suggest that the service user, other key relatives/carers and NTW staff will jointly agree a list of recognised individuals that will benefit from this support.

While concerns about the financial cost of travel should be helped by NTW's travel support, we

have also heard concerns about the time and inconvenience that a move to Hopewood Park and St George's Park in particular would cause. People have said that increased travelling distances may mean that they have to reduce the frequency of their visits.

- **Older people's care:** We recognise that inpatient treatment in a modern facility is important. We also note that having adequate, appropriate outside space helps recovery and patient experience and would therefore encourage the CCG to find a solution that balances this requirement with the points made above.
- **Commission on Acute Adult Psychiatric Care (CAAPC) report:** This report was published in February 2016, just prior to the consultation close date. We are pleased that we do not appear to have many of the concerns and issues highlighted in the report, however, we draw the CCG's attention to the following recommendations that we believe are particularly relevant to this consultation
  - *The practice of sending acutely ill patients long distances for non-specialist treatment is phased out nationally by October 2017* - whilst we acknowledge that Sunderland and Morpeth would probably not be considered to be long distances in the terms of this report, the principles behind this recommendation should be considered in the context of Deciding Together.
  - *Commissioners, providers and Strategic Clinical Networks...undertake a service capacity assessment and improvement programme to ensure they have an appropriate number of beds as well as sufficient resources in their Crisis Resolution and Home Treatment teams to meet the need for rapid access to high quality care by October 2017* - we recognise that NTW is currently a net importer of patients and would hope that all concerned work together to ensure that there is appropriate inpatient and community treatment capacity locally (i.e. in Newcastle and Gateshead).
  - *There is better access to a mix of types of housing - and greater flexibility in its use - to provide for short-term use in crises...* - we would like to see this properly considered when developing improved community services.
  - *Patients and carers are enabled to play an even greater role in their own care as well as in service design, provision, monitoring and governance* - we would like to see ongoing and increased service user involvement in the design of the final model of care as well as in monitoring its effectiveness and impact on outcomes and patient experience.
  - *A Patients and Carers Race Equality Standard is piloted in mental health...* - in particular we would like commissioners and providers to review the information relating to those accessing the services covered by Deciding Together and review demographic groups that show unusually high, or low, use (e.g. Asian women).

## Summary

Healthwatch Newcastle is generally satisfied that the pre-engagement and consultation have been well conducted although we would ask that our concerns about involvement of those with dementia, their relatives and carers, and of people in Gateshead are noted. We feel that there has been a willingness to try new things and that the CCG has been open to criticism and feedback in an effort to have a dialogue with the people of Newcastle and Gateshead.

We ask that the CCG makes it clear that people will have the opportunity to make further comment during the consultation feedback phase and that, as this will be after the travel and transport plan has been published, they will be able to take the plan into consideration.

We feel that the concerns around transport and travel time and proximity more generally are huge and valid, so any option that includes travel beyond Newcastle and Gateshead would have to show immense benefits in other areas to balance out this drawback.

We encourage the CCG and NTW to continue their determination and increase their effort to include the local population generally, and service users, relatives and carers in particular in the design of the new model once a decision has been taken.

15 February 2016