

Service specification for haemophilia and related bleeding disorders (adults and children)

Do you agree with the revisions to the service specification compared with the current version?

- ☒ strongly agree
- ☐ agree
- ☐ neutral
- ☐ disagree
- ☐ strongly disagree

Please share your comments in the below text box.

Healthwatch Birmingham recognise that there are significant improvements towards more patient centred care in the revisions to the service specification. We are particularly please to see the greater emphasis on non-medical interventions to support people, and the more flexible approaches to be used when delivering care. We hope that networks will allow for further improvements to care for people, and for best practice to be shared and implemented.

Do you agree with the statement in relation to haemophilia networks?

- ☐ strongly agree
- ☒ agree
- ☐ neutral
- ☐ disagree
- ☐ strongly disagree

Please share your comments in the below text box.

We agree with the statement in 7.3 on clinical networks and their focus but would like to see a greater role for patient participation, involvement and engagement as part of the networks. A statement to include service user views in discussions does not go far enough in how these voices should be collected by services and acted upon. Services should consider how they ensure that all service users and their care givers feel comfortable to share their views and reassured that these will be heard and acted upon by networks. Without additional details, it may lead to inequalities in the service users' views heard.

We also feel that service user representation where appropriate should be part of the network activities and discussions.

It is good to see that widening service user access to clinical research trials is an aim of the networks, as this has traditionally been an area that has lacked diversity, leading to less effective treatments for some people.



Do you feel that the revised service specification provides adequate patient voice, and promotes patient-centred care?

- strongly agree
- agree
- neutral
- disagree
- strongly disagree

Please share your comments in the below text box.

Healthwatch Birmingham are pleased to see the greater flexibility offered in specialised service user pathway and that the use of in person or remote clinic will take into consideration user preference. We often hear from people in Birmingham that having choice and flexibility of how appointments are accessed is important as individual people's circumstances suit different methods. We are pleased to see that outreach appointments may be offered closer people's homes, and home treatment and self-management will be supported, as time and cost of travel can be barriers to attendance and engagement with services.

We would like to see a commitment made to regularly collect feedback about CCC services, and to act on these to improve the services offered to people. Whilst there is a commitment to include service users' views as part of clinical network discussions, there should be a clearer requirement to engage with service users and carers as part of gathering these views, and demonstrating the value of patients voices by acting on issues raised.

We are pleased that the psychological impact of these conditions, and of the Infected Blood Inquiry and its consequences have been recognised in the service specification, and hope that people accessing services feel their emotional and psychological wellbeing is now given greater consideration as part of their care.

Are there any associated care-givers, modalities or specific related morbidities which you feel are missing from the revised service specification?

Please share your comments in the below text box.

Healthwatch Birmingham notes that the EHIA has identified the need to collect more accurate information on the racial and ethnic backgrounds of service users, and that equality issues are being identified and monitored. This information and the process of identifying equality issues may lead to further morbidities being identified, and when looking at cultural identities of service users, may identify additional care-givers.

Do you have any other comments you would like to share with us?

We were pleased to see the stakeholder engagement reports presented as part of the papers for this consultation on this service specification. It clearly shows the work that has already happened prior to the consultation, and how different views have been listened to and addressed. This



reassures people that their comments and views do matter, and that services are aiming to best meet the needs of service users and their families.

