

## Healthwatch Birmingham and Healthwatch Solihull response to Birmingham and Solihull Health Information Exchange

Healthwatch Birmingham and Healthwatch Solihull welcome the opportunity to respond to the consultation on the *Birmingham and Solihull Health Information Exchange*. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

- Public Involvement.
- The extent to which the proposed Health Information Exchange address the needs of Birmingham citizens.
- Information required by Birmingham Citizens to make an informed choice

### Public Involvement

Healthwatch Birmingham and Healthwatch Solihull note that information has been available to people, including a FAQs document. We note that people have had the option of emailing for further information and requesting information in different formats. However, there is not a phone number or postal address to allow anyone without digital access to respond. If other engagement activities have taken place, we would like to see these publically and clearly displayed to inform and allow public involvement.

We welcome that people have been given the opportunity to have ongoing involvement in the Health Information Exchange. It would be helpful for people to know if there was any public involvement in developing the plans presented in this consultation.

Healthwatch Birmingham and Healthwatch Solihull would be interested in the engagement report of this consultation, to see how effective this has been at speaking to all people in both areas. We question whether the timing of the consultation, during lockdown and over the Christmas period, has been the best time to consult on such an important matter.

### Health Information Exchange

We welcome the commitment to increase the continuity of care with the Health Information Exchange for patients in Birmingham and Solihull. We hear regularly from PPSuCs how important this is to them during the course of our work. Below is some of the feedback we have heard:



*Centralised computer systems. If you go to the hospital, they should be able to access medication records.*

*Better communication needed between professionals if you are suffering from more than one problem, e.g. if you have a heart problem and need back surgery.*

*No one knows when we may need health services but confidence in the joint working of partner agencies is of utmost importance.*

*It's like the GPs don't have enough time to read everything through - I actually feel for them. In this instance I can see where the failings occurred - the consultant didn't actually highlight on the letter that further investigation was needed (even though it was) and the GP didn't pick this up either. It was only through me reading up ... I realised I needed this abnormality looking at to determine the scale of the issue*

We have also heard how important it is for people to not have to repeat themselves

*Improved communication between different services – don't want to repeat and share my story over and over*

*Please do not repeat questions more than once*

*I felt that I had to explain my story, time and time again, as the services are not integrated. The services are very fragmented, I felt I was passed along the health system, repeating my story, and reliving the trauma. It is unbearable.*

We understand the scheme covers Birmingham and Solihull. However it is unclear from the information provided whether it covers the area of West Birmingham, and all services within this area. We feel this needs to be clarified urgently for all services involved to understand.

Another area of uncertainty about the Health Information Exchange is around private providers and whether they will have access to the information or be able to update it. This is especially important for private providers that are providing care on behalf of the NHS. We are also aware that members of the public in both Birmingham and Solihull may be accessing services from private providers via apps, including primary care from private GPs.

It would be useful to know how this scheme assimilates with other national information sharing schemes that are currently being developed.

## **Further Information**

At Healthwatch Birmingham and Healthwatch Solihull we believe that people need clear information to be able to make informed decision about their care. As such, we feel the Health Information Exchange needs to clarify in more detail about the use of previous



consent and objections to sharing records. It is important that there is clarity for service users on the type of information that will be shared for established purposes and the exceptional circumstances or one-off decisions to share information. We have received feedback more recently, where information shared with one organisation was shared with another organisation against the wishes of the service user as this impacted decisions around their care package. We recognise that GDPR has been highlighted in this consultation as crucial to the implementation of the information exchange plan. We would like to reiterate that the following needs to be considered when sharing information as per the NHS England's information sharing policy:

- **How individuals are made aware of the information sharing?** Have individuals been provided with the fair processing information as required by the GDPR? How is it ensured that individual's rights are respected and can be exercised? For example, how can they access the information held once shared?
- **What the legal basis for data protection purposes is?** Organisations must identify the lawful basis (e.g. meeting statutory duties) for processing and, where necessary, a condition for processing special categories data (e.g. managing a health and care service).
- **If the information is confidential,** what is the legal basis that complies with the common law duty of confidence? This can be consent (implied or explicit), overriding public interest or required or permitted by law

The information provided with the consultation also talks about exemptions of the information sharing on sensitive record. We feel it would be useful to give people the choice to opt in or out of sharing these records, including other areas they may feel is sensitive such as mental health services and addiction treatment.

## Conclusion

The ability to exchange patient information across clinical contexts is indeed important as it has the potential to improve quality and increase patient satisfaction. We are aware that one of the key barriers to information exchange and data sharing has been the connectivity of systems and the existence of different infrastructures. Thus impacting efforts towards interoperability and data sharing which is crucial to the success of any information exchange plans. We hope that the Health Information Exchange plans will support the improvement of the adoption of electronic records across different organisation in Birmingham and Solihull and the establishment of health information infrastructure. It is important that there is buy-in from staff to introduce and use the information exchange infrastructure as there as the incentives are different for organisations across primary and secondary care.

We welcome your call for continued engagement with service users and we hope to see further engagement with PPSuC' in the implementation of the Health Information Exchange System and evaluating the use, barriers and the results of information exchange.



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Yours Sincerely,



Chipiliro Kalebe-Nyamongo  
Research and Policy Manager



Sarah Walmsley  
Data & Insight Officer

