

FEEDBACK FROM THE 11 and 12 JULY 2018 CITIZEN'S JURY

1. INTRODUCTION

- 1.1. This report on the Citizen's Jury sets out the recommendations from the jury members and provides an overview of the methodology and discussions that took place over the course of the two days.
- 1.2. This report will be shared with jury members on the 20 September so they can see and validate how their recommendations and discussions are being presented as well as hear how they are being taken forward through the Council's decision making processes. The edited video of the jury will also be shared so participants can give their consent prior to publication on the Council's website.

2. RECOMMENDATIONS

- 2.1. At the end of the second day of the jury, the members discussed the issues and devised a set of recommendations. Each of the recommendations was subject to a secret ballot, to ensure that everyone was able to express what they thought. The Citizen's Jury made the following recommendations:
 1. ASC and Health should share records as part of the local care record
 2. ASC and Health should undertake periodic checks of records to confirm they are current and accurate
 3. Records must only be shared with agreed roles and in line with appropriate procedures and governance arrangements (and supported by appropriate training)
 4. Information could be shared with providers, commissioned by Health and Social Care
 5. Records shared under these arrangements should be current
 6. Be clear on what is fact and what is opinion and use plain speak
 7. Promote peoples confidentiality and data protection rights in a leaflet held in a file by the service user and on the websites of the organisations sharing the information
 8. Records should only be shared on a need to know basis
 9. Care agencies must take steps to provide assurance to the Council that care workers are trained to write good quality and accurate notes and work within GDPR guidance

10. Consider a standardised approach to care planning to support data record sharing
11. Before sharing information with third parties not covered by the local care record we should ask service users for their consent
12. Design clear principles for staff (for example, treating people like they are a member of your family, consent at every stage when sharing information with third parties who don't have access to the local care record and the 5 rights for information sharing)

The results of the voting evidence the high degree of support from all jury members for these recommendations.

3. BACKGROUND INFORMATION

- 3.1. In April 2018 the council decided that it would convene a Citizen's Jury to look at the issue of sharing records between the providers of health and social care. We wanted to make sure that adult social care service users have the opportunity to raise any concerns they may have about the sharing of records. We wanted service users to feel comfortable and confident with the type of information that could potentially be shared and with who for the purposes of supporting a more joined up response to their needs.
- 3.2. Manchester University and partners used the Citizen's Jury model of engagement to determine whether the NHS should share patient data with third party organisations for health and medical research. This seemed an interesting model to follow for our own enquiries into developing the protocols we should use to deliver local shared records between health and social care. We also researched the practice and experience of use of citizen's juries elsewhere.
- 3.3. We chose the Citizen's Jury model for engagement because it was felt that this topic is complex and requires informed consideration of the issues balancing the improvements that record sharing can bring with people's right to privacy. However we made a number of adaptations to fit the environment in Southwark and the nature of the topic. The key changes were:
 - a. The pool of constituents were drawn from social care users rather than the general population
 - b. The framing of the discussion and questions were prepared by Southwark
 - c. The jury were broken into smaller groups to discuss the issues
 - d. Some background information was shared with jurors before the sessions

- e. We did not test views before the sessions began.
- 3.4. We agreed that the jury would discuss the issues and influence the decision that Southwark makes about:
- Sharing records
 - Who has access to shared records
 - What information is shared

Any final decisions will be made by the Council.

4. METHODOLOGY

Recruiting the Jury

- 4.1. The jury members were selected by invitation. The aim was to recruit a diverse range of users who, as far as possible were representative of Southwark's Adult Social Care service users. We wrote to a random selection of over 500 people who received social care in the previous 12 months, advertised the opportunity to take part through community organisations, the Clinical Commissioning Group (CCG) and Healthwatch.
- 4.2. Prior to sending out the invitations we analysed the data we held on social care service users so we could select applicants based on the demographics of users. The criteria were that jurors had to have received a social care service in the last 12 months, live or care for someone living in Southwark and be over 18.
- 4.3. 15 service users were initially recruited. However, due to people's individual circumstances, five service users were unable to take part on the actual jury days with one juror who attended on the first day, being unable to attend on the second day. This resulted in a jury made of up nine people ranging in age from 36 to 79; there were three men and six women in attendance, four of the jurors were from black and minority ethnic groups. The jurors used, or had used, a range of services to address their social care needs.

The Jury programme

- 4.4. The event was chaired and hosted by Janice Lucas, from the Institute of Public Care an organisation independent from the Council. We felt it was important to promote trust and confidence that the chair did not have a stake in the outcome but was someone who was familiar with the service area and could support the jurors to ask questions if needed. The facilitators were from the community engagement team and adult social care team. The participants were divided into two groups throughout the event to facilitate discussion and ensure there was an opportunity for everyone to have their say.
- 4.5. The jury took place over two days with a two hour introductory session

taking place the week before. We thought it would be helpful if everyone had had an opportunity to meet and get to know each other and the project team and make sure that they were clear about the purpose of the event and were familiar with the venue. Jay Stickland, Director of Adult Social Care, attended the introductory session and jurors were provided with some background information about the topic to take away and reflect on before the jury started.

- 4.6. The first day of the jury on the 11 July was about hearing the expert witnesses and having an opportunity to ask questions. The first two witnesses were service users who were interviewed about their experiences of record sharing in their homes and shared their thoughts in the form of video statements. This set the scene and provided a clear focus on the purpose and impact of sharing records from a service user's perspective. The rest of the morning session was focused on the background to shared records and some of the risks linked to data storage and sharing; the afternoon had a range of service providers talking about their experiences of sharing records within health and social care and what they saw were the benefits and issues as well as why they would like to see this extended via the delivery of the local care record.
- 4.7. There were some particularly powerful contributions which resonated throughout the discussions, these were the two video statements from a user of adult care services and health services in the home and a carer of someone living at home with a care package and multiple health needs, the customer rights provided through the new General Data Protection Regulation (GDPR), the service manager who spoke about the newly integrated Southwark Intermediate Care service and the care manager at London Care.
- 4.8. The second day was devoted to discussion of the evidence presented on day 1 using a series of questions to structure and facilitate debate. We asked jurors the following:
 - a. What do you think will be the benefits of shared local records?
 - b. What do you think are some of the risks about record sharing?
 - c. Which (if any) organisations do you think should be able to access your adult social care records?
 - d. What information held by adult social care do you think should be shared?
 - e. What information held by adult social care do you think should not be shared?
 - f. Can you explain why you have answered the way you have to questions 4 & 5?
 - g. What information do you think should be shared with externally commissioned service providers such as home care agencies or their staff?

- h. On balance do you think that adult social care records should be shared with others involved in your health and social care?
 - i. Do you have any recommendations to make?
- 4.9. The discussions about questions a – h helped to formulate the recommendations making the final discussion fairly straight forward.

5. THE DISCUSSIONS – Summary of feedback from facilitated discussions

- 5.1. The jurors were supportive of the desire to share records and the focus of much of the discussion was about how do we ensure that the records that are being shared are of good quality and there are appropriate processes in place to protect the service users. The common goal should centre on how we best achieve a service that surrounds the patient or client and the protocols needed to make this happen easily.
- 5.2. The benefits of record sharing identified by jurors were about not having to retell their stories, saving time, having more accurate and responsive services and the ability to take timely and appropriate action, supporting a multidisciplinary approach and ensuring the service will have a total picture of the person. One theme kept cropping up about the strength of record sharing as a tool to create a person-centered service.
- 5.3. People were most concerned about the accuracy of their records and their ability to challenge successfully where they felt the information was wrong. They felt that with sharing there was greater risk of misinformation being held by a wider group of people, this in turn raised concerns about how this might be acted on by a wider pool of staff. There was a concern about people seeing their whole record where this may no longer be relevant and how this might prejudice care and health providers.
- 5.4. The participants were concerned that inappropriate guidelines in place could lead to inappropriate access to records. They were concerned about the use of jargon in these records if they are being accessed by a wider pool of people leading to misunderstanding and inappropriate action. They also raised the value of records being signed by the individual that is writing it so errors could be corrected. People were concerned about hacking, staff having access to more information than required to do the task, and the misuse of data.
- 5.5. Participants knew little about their rights regarding the data held about them and were clear that more information should be provided about this, with professionals explaining these face to face, leaving information in their files and information on the website.
- 5.6. There was discussion about how we could ensure that the care records were

- Accurate
- Unbiased
- Up to date
- Relevant

The solution was seen as a key training need around being able to identify the difference between fact and opinion; having the right procedures and guidance in place; review of the information annually and on request; making people aware of their rights.

- 5.7. In discussions about what should be shared with commissioned services, it was felt that information sharing should be with an appropriate level of management who would be responsible for filtering this information to front line staff according to the procedures and guidance alluded to in the previous point, but felt that the current care and support plans, safeguarding information and needs assessment were the most appropriate.
- 5.8. Jurors were impressed with the “five rights for sharing” outlined by one of the witnesses, “you share for the right reason, using the right method, with the right person, sharing the right amount of information to make informed decisions, and the right information and for the right outcome”. Many felt that these were a good framework to use for developing the protocols for information sharing.
- 5.9. A wide range of organisations were seen as appropriate to share records with such as the ambulance service, statutory health services, charities that support people, homecare providers, council commissioned services, and groups such as falls clinics, hearing clinic, mental health teams, but only registered and supervised staff groups with relevant tasks. Again the group caveated this with concerns about appropriate procedures to protect the interests of the service user.
- 5.10. In general the discussion across the two days were about the accuracy of records and how up to date they are, how service users will know the information is being shared and the importance of the information in the records being in plain English. People were keen to ensure that users knew their rights, making sure there is a consistent approach across such a varied range of providers. People were interested in the ideas about auditing of records as a safeguard and how we decide what is relevant to share.
- 5.11. Overall the project met the engagement goals identified above. The project resulted in a clear set of recommendations from service users that will be used to inform and influence information sharing in Southwark. Feed-back from the participants was they enjoyed the sessions; the majority of the participants were new to engagement activity.

