

If I've told you once...

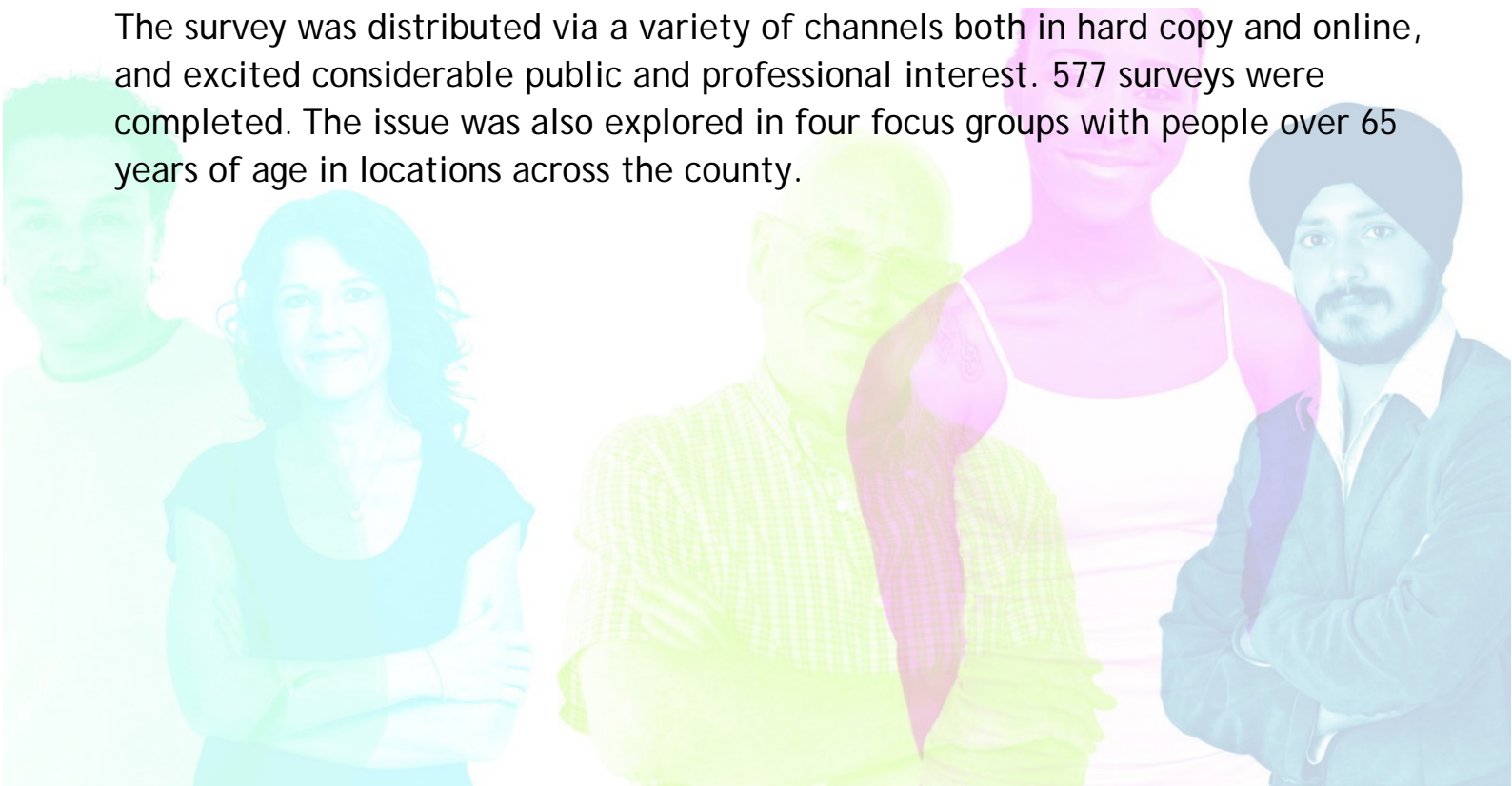
People's views on record sharing between the health and social care professionals involved in their care

October 2015

Summary report

In the summer of 2015 Healthwatch Surrey carried out a survey investigating the views of people in Surrey around sharing of health and care records between the health and care professionals involved in their care. The survey was commissioned by Surrey County Council as data sharing is considered a key enabler to integrating health, care, and support services, and hence of providing greater person-centred coordinated care.

The survey was distributed via a variety of channels both in hard copy and online, and excited considerable public and professional interest. 577 surveys were completed. The issue was also explored in four focus groups with people over 65 years of age in locations across the county.



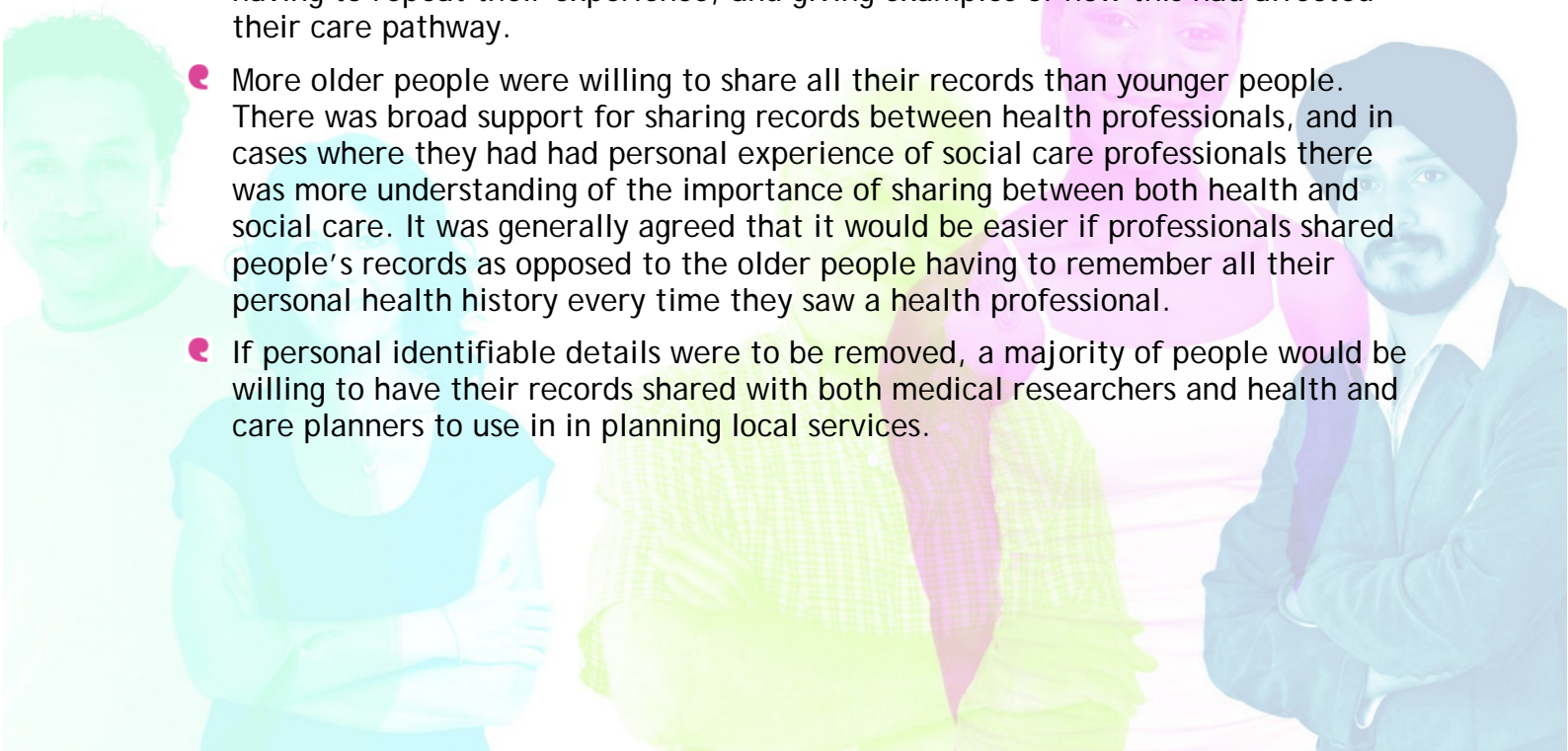
Findings

- Over a third of respondents were unaware prior to taking part in the survey that health and care records are not readily shared between health and care professionals.
- 58% had personal or family experience of having had to repeat their stories to different health or care professionals, or of their care pathway being affected by lack of record sharing, and over half of these shared their story with us.
- 91% of respondents would **share all or part of their records**. Only 7% would opt out of sharing completely.
- 94% of respondents would **share with all or some of the health and care professionals** involved in their care, nearly two thirds of these would be happy to share with all the relevant professionals.
- Nearly all respondents were willing to have their records shared between GPs (96% in favour) and hospital doctors (93%). Nearly three quarters were happy to share with other medical staff giving care whether in a GP surgery or a hospital environment (75%, 69%). Less than half of respondents were happy about having records shared with social care professionals (45%), especially home care workers (30%).
- Both survey comments and focus groups suggest there is greater trust in and understanding of the role of medical/health professionals than of social care professionals.
- The most common area of concern with respect to record sharing was **access by third parties**. Other common concerns centred on **accuracy** of the records being shared, **confidentiality**, and **privacy**. People were less concerned about the issue of sensitive information being shared.
- The majority of people (77%) felt that it should be a combination of patient and professional who decide how records are shared. (Patient and doctor together, 42%, or patient, doctor and social care practitioner, 35%).
- Most people were willing for information such as current/most recent medications, list of allergies, vaccination record to be shared but less content to share information on social care and support packages.
- If name, address and NHS number were removed from the records, 61% (an additional 18% said 'possibly') of respondents would agree to records being shared with medical researchers, and 57% (an additional 21% 'possibly') with health and social care planners to help plan local services.
- Older people were generally more willing to have their records shared between the professionals involved in their care. In focus groups with over 65s there were comments from people about the difficulty of remembering all the relevant details of their health history and keeping lists or using the 'message in a bottle' scheme in order to ensure they had all their health and care details to hand.

Conclusions

If the parameters of medical and care record sharing are kept within the confines of the medical and care professions, and there are procedures in place to ensure security, confidentiality and accuracy, there is strong support from survey respondents for sharing all or part of their health and care record with all or some of the health and care professionals involved in their care.

- When the limits of the sharing were clear, the vast majority of people were in favour of sharing. When the discussion took off on its own, for example on social media or at engagement events, it frequently moved to concerns about third party access by insurance companies, private companies, family members. It was necessary to constantly explain the boundaries of the sharing to contain anxiety about third party access.
- Third party access, security, confidentiality and accuracy of the records being shared were the main concerns around sharing of health and care records, and even amongst those agreeing to share, reassurance was required that these concerns were being addressed.
- People were keen to have a role in deciding for themselves who could see their records. They wanted to have personal access so that they could verify the contents and check the accuracy of the records.
- There was a marked divide between willingness to share between medical/health professionals and willingness to share with social care professionals. Comments suggested a lack of understanding of the professional status of social workers and a general lack of trust of social care professionals. This may have been due to the fact that many people had had less contact with social care professionals and so had less personal experience upon which to base their views, but it also suggests that there is a need for more explanation and reassurance around the roles and work of social care professionals in general.
- A third of respondents to the survey were not previously aware that their records were not already readily shared between the professionals involved in their care. In some cases this served to enlighten respondents as to why they had to keep repeating their story. Many related stories demonstrating their frustration at having to repeat their experience, and giving examples of how this had affected their care pathway.
- More older people were willing to share all their records than younger people. There was broad support for sharing records between health professionals, and in cases where they had had personal experience of social care professionals there was more understanding of the importance of sharing between both health and social care. It was generally agreed that it would be easier if professionals shared people's records as opposed to the older people having to remember all their personal health history every time they saw a health professional.
- If personal identifiable details were to be removed, a majority of people would be willing to have their records shared with both medical researchers and health and care planners to use in planning local services.



Demographic information: Of those who provided personal information, 68% were female and 32% male, 15% considered themselves to have a disability, 96% categorised themselves as White, 3% Black and 1% Mixed race. 31% were under 50 years of age, 39% were between 50 and 64 years, and 29% were over 65 years of age.

N.B. On 1 October 2015, as this report was being published, a new legal duty came into effect requiring health and adult social care bodies to share information where this will facilitate care for an individual. *Health and Social Care (Safety and Quality) Act 2015, Chapter 28.*

http://www.legislation.gov.uk/ukpga/2015/28/pdfs/ukpga_20150028_en.pdf./www.legislation.gov.uk

The full report is available on the Healthwatch Surrey website at:
www.healthwatchesurrey.co.uk

People can contact Healthwatch Surrey about any concern, experience, issue or feedback they wish to share about a health or social care service in Surrey.

Telephone: 0303 303 0023 (local rate number)

Text (SMS): 07592 787533

Text Relay: 18001 0303 303 0023

Email: enquiries@healthwatchesurrey.co.uk

Website: www.healthwatchesurrey.co.uk

Or pop into any of the **Citizens Advice Bureau** in Surrey

Healthwatch Surrey also provides free, independent support with making a complaint about an NHS service. Contact our partner, Advocacy in Surrey on:

Tel: 0300 030 7333

Text (SMS): 07561 392818

Email: advocacy@healthwatchesurrey.co.uk

A comprehensive list of other advocacy support services in Surrey, including mental health advocacy, can be found on the Surrey County Council website at

<http://www.surreycc.gov.uk/social-care-and-health/adult-social-care/adults-with-physical-or-hearing-or-visual-impairments/advocacy-and-advice-services-for-adults>