

If I've told you once...

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

October 2015.

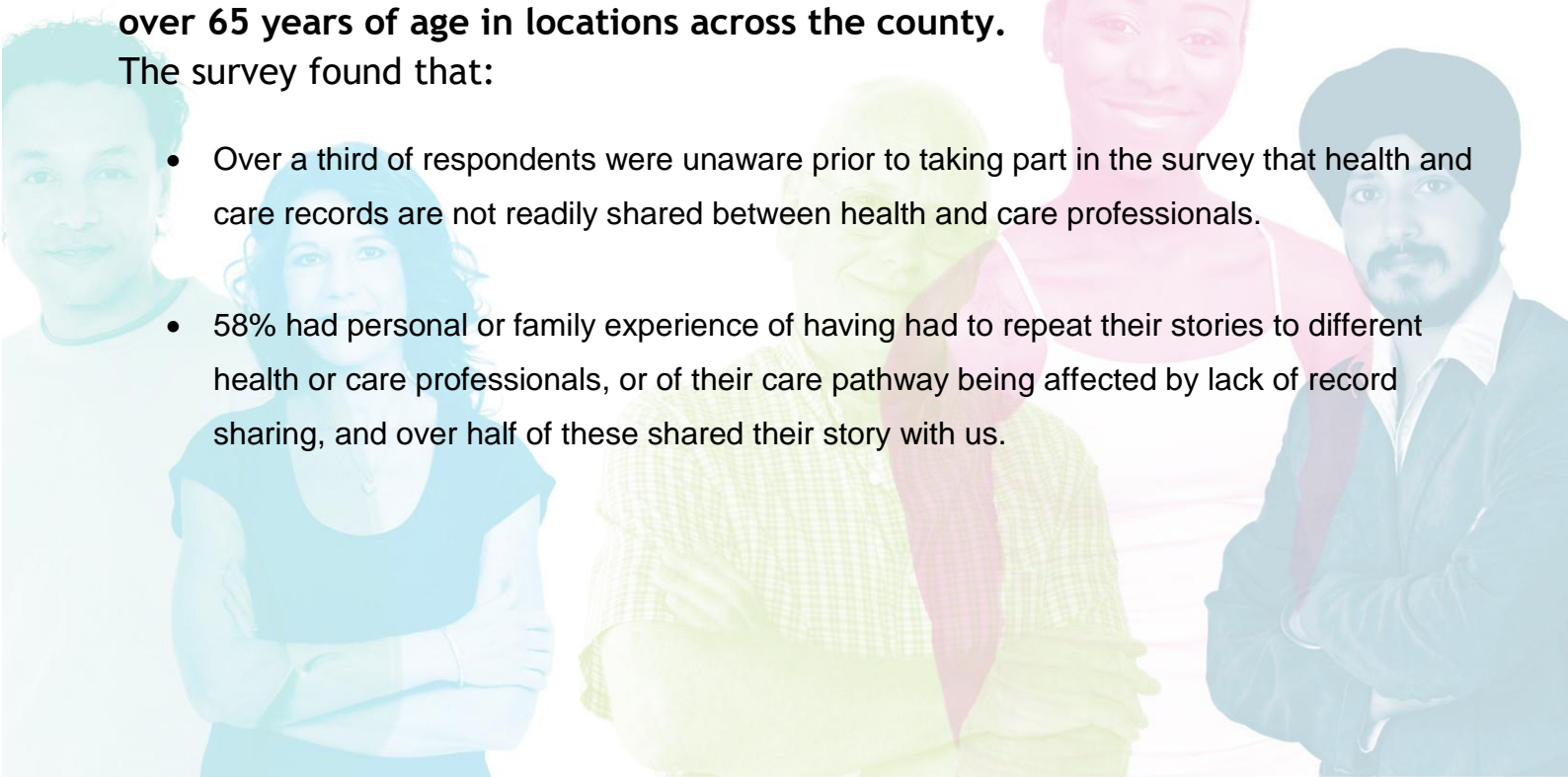
Summary report

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. Surrey cc were interested in the views of the people of Surrey

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.

The survey found that:

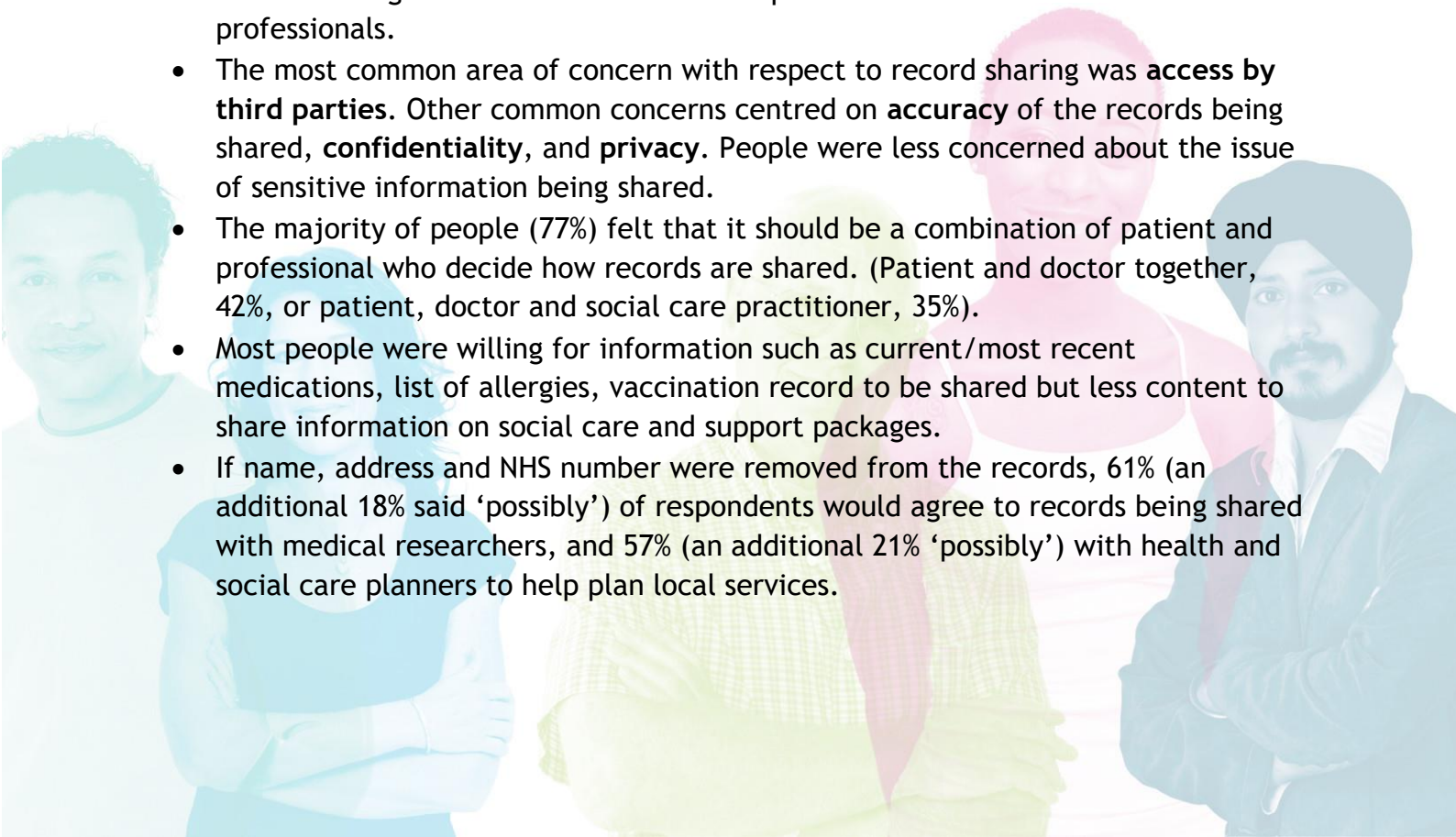
- Over a third of respondents were unaware prior to taking part in the survey that health and care records are not readily shared between health and care professionals.
- 58% had personal or family experience of having had to repeat their stories to different health or care professionals, or of their care pathway being affected by lack of record sharing, and over half of these shared their story with us.



Findings:

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.

- 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 (97% in favour) and hospital doctors (94%). Nearly three quarters were happy to share with other medical staff giving care whether in a GP surgery or a hospital environment (77%, 72%). Less than half of respondents were happy about having records shared with social care professionals (49%), especially home care workers (33%).
- Both survey comments and focus groups suggest there is greater trust in and understanding of the role 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 older 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.

Recommend: More person-centred care, where people have to tell their story only once, have one point of contact, and feel they are being listened to.

Recommend: Strong safeguards and staff training are in place to ensure confidentiality and guard against breaches of information to third parties.

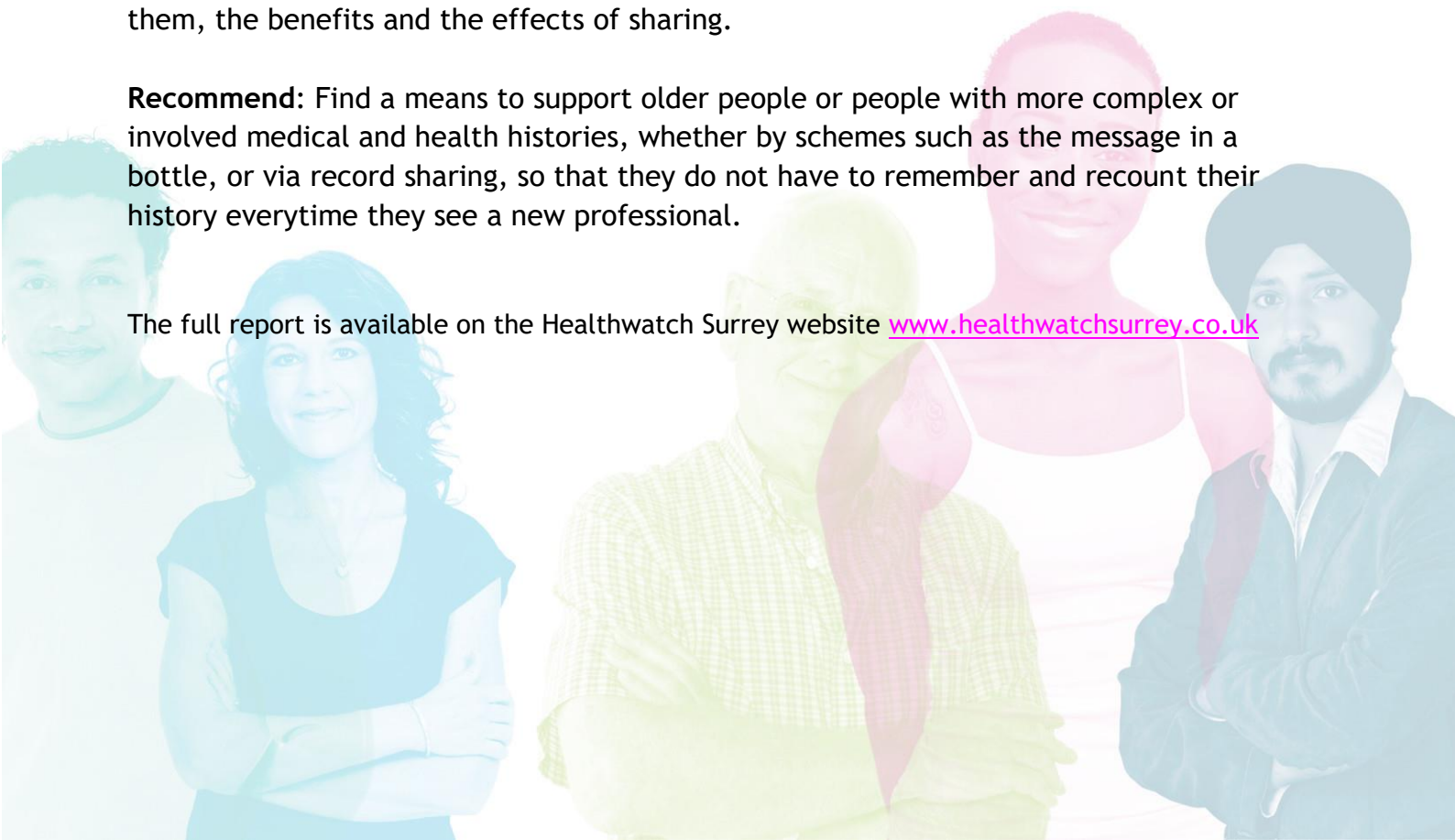
Recommend: Clarity and reassurance around the confines of the sharing. Ensure that the boundaries of the sharing are controlled and provide reassurance that this is the case, that records will only be shared between the health and care professional involved in people’s care, and will not be passed on or accessible to third parties not involved in people’s care.

Recommend: Give people the choice about how much of their record is shared and with whom. Provide people with the option to check their records themselves if they wish, and the facility to request records be amended if inaccurate.

Recommend: Further discussion around the divide in confidence and trust between health and social care professionals. More information around the role of different health and care professionals, the way people’s information will be shared between them, the benefits and the effects of sharing.

Recommend: Find a means to support older people or people with more complex or involved medical and health histories, whether by schemes such as the message in a bottle, or via record sharing, so that they do not have to remember and recount their history everytime they see a new professional.

The full report is available on the Healthwatch Surrey website www.healthwatchsurrey.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](tel:03033030023) (local rate number)

Text (SMS): [07592 787533](tel:07592787533)

Text Relay: 18001 0303 303 0023

Email: enquiries@healthwatchesurrey.co.uk

Website: www.healthwatchesurrey.co.uk

Or pop into any of the **Citizens Advice Bureaux** in Surrey. A list of the Citizens Advice Bureaux in Surrey is available on the Healthwatch Surrey website.

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

Email: advocacy@healthwatchesurrey.co.uk

Text (SMS): 07561 392818

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>

