



If I've told you once....

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

October 2015



DATE: _____
INSTRUCTIONS OFFICER: _____
NAME: _____
ADDRESS: _____
POSTCODE: _____

I have read the information and I understand what is being asked of me. I agree to provide the information requested and I understand that the information will be used for the purposes stated above.

South London and Maudsley
NHS Foundation Trust
1001 Lambeth Road, London SE16 5JH



Contents

1. Foreword	4
2. Summary	5
3. Background	6
4. How the research was carried out	7
5. What did people tell us?	8
Survey:	8
Focus Groups:	21
6. Conclusions and recommendations	23
7. Next Steps	25
8. Contacting Healthwatch Surrey	26
References	27
Appendix 1: Survey distribution	28
Appendix 2: Distribution of responses across Surrey by postcode	30



1.

Foreword

A key role for Healthwatch Surrey is to empower people to shape and challenge the services they use. In doing so we aim to support the health and social care system to put the aspirations and perspectives of people that use services at the centre of its decision making.

This report captures and reflects the views of hundreds of local people on the sharing of personal data records between health and care professionals. By publishing the findings and recommendations we are seeking to influence and bring benefits to the health and social care system agenda of integrating services, for which the sharing data is a key enabler of potential improvements.

The messages contained within the report are loud and clear. There is strong support for the sharing of all or part of people's health and care records with the health and care professionals involved in their care. But there are equally important messages about the limits of this support and a strong desire for people to be involved in decisions about the sharing of their data.

On behalf of Healthwatch Surrey, I would like to thank all the people who took part in the project, either by distributing the surveys or by giving their time to tell us about their experiences and share their views with us. We will contact local commissioners to seek responses to the views presented, following which we hope we will all start to see the differences your contributions have made.

Peter Gordon,
Chair Healthwatch Surrey





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.

The survey found that: 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.

- 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.
- 91% of respondents would share **all or part of their records**. Only 7% would opt out of sharing completely.
- 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.
- 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 medical/health professionals than of social care professionals.
- 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.
- It was necessary to constantly restate the boundaries of the proposed record sharing and reaffirm that records would be shared only between health and care professionals involved in the person's care. When the discussion moved beyond these confines, particularly on social media, it escalated fairly quickly into concerns over third party access.
- 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 in order to ensure they had all the details to hand.



3.

Background

Surrey County Council approached Healthwatch Surrey with a view to carrying out a survey consulting people in the county about their opinions on sharing of their health and care records between the health and care professionals involved in their care.

The purpose of the research was to:

“approach patients and people we offer care and support to, to understand their views around the sharing of their personal data in health and care records, We want to improve people’s outcomes and experiences of care. Data sharing is a key enabler to integrating care and support services with a view to improving the planning and delivery of these services.” SCC Brief May 2015

As defined by the NHS England commissioned National Voices narrative, ‘Integrated care’ means ‘person centred coordinated care’ (1). Co-developed with the health and care system by National Voices, a grouping of 130 health and social care charities, the narrative produced a series of ‘I’ statements about what matters most to patients and service users. On the subject of communication key statements included:

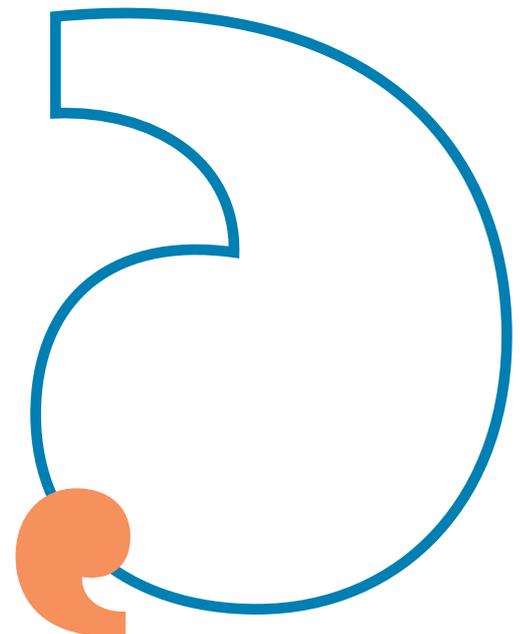
-  I tell my story once.
-  I am listened to about what works for me, in my life.
-  The professionals involved with my care talk to each other.
-  We all work as a team.
-  I always know who is coordinating my care.
-  I have one first point of contact.

Research using ‘I’ statements to develop measures of people’s experiences of integrated care reported that a common theme was people’s frustration at having to ‘repeatedly tell their story and history’, the sense that there is little co-ordination between health and social care and that they are never speaking to the same person. (2)

A General Medical Council review of public and professional attitudes to privacy of healthcare data suggested that people are generally “sympathetic to data exchange between health professionals within the NHS as long as it leads to improved care and information is secure”. (3) However it also found that the greater the distance from those directly involved in patient care, the greater the concerns around access. (3)

Common concerns about use of medical records and related privacy issues included: Who can access the data and why, personal control, social stigma, and financial implications (job applications, insurance). The review also referenced a Gallup poll which suggested that women are more likely to have confidentiality concerns than men and that cultural values may vary with the generations. (3)

Note: On 1 October 2015, as this report was about to be 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. (4)





How the research was carried out

After reference to this existing literature, and the project brief, a draft questionnaire was drawn up. This was trialed at an Eating Disorders Awareness event at Surrey and Borders Partnership NHS Foundation Trust on 8 May.

There was a lot of interest in the survey, and it also became apparent that some people were unaware that their records were not currently shared. The questionnaire was amended based on responses and an initial question was added immediately after the introductory paragraph, asking people if, prior to reading this paragraph about health and care record sharing, they had been aware that their records were not shared.

The final redrafted survey then opened on Survey Monkey on 22 May and closed on 20 July 2015. 577 responses were received.

The survey link was distributed via the Healthwatch Surrey website, e-Bulletin and contacts, as well as on social media, via other voluntary organisations such as Surrey Youth Focus and Surrey Minority Ethnic Forum, via Universities, Citizens Advice Bureaux, Surrey Hubs and Surrey County Council. The subject excited interest and comment across both the public and professional spectrum. A press release resulted in newspaper coverage and a radio interview. It inspired debate on social media, particularly on Streetlife and Twitter, it was tweeted and retweeted many times.

Copies of some of the tweets and a couple of social media conversations illustrating the diverse views are included as an appendix on our website:

www.healthwatchesurrey.co.uk.

Hard copies of the questionnaire were also printed and distributed at engagement events such as Armed Forces day in Guildford, and Surrey Independent Living Council Fair in Epsom, and were used to engage with the public at a range of venues such as a GP surgery and a Children's Centre.

A full distribution list is provided in Appendix 1.

In addition, at the time the survey was being carried out, Healthwatch Surrey was undertaking another project seeking the views of people aged over 65 on access to primary care. During the focus groups, an additional question was added asking people their views on their records being shared, with the aim of delving a little deeper to find out the reasoning behind their responses. Focus groups were held in Leatherhead, Oxted, Ash and Godalming.



5.

What did people tell us?

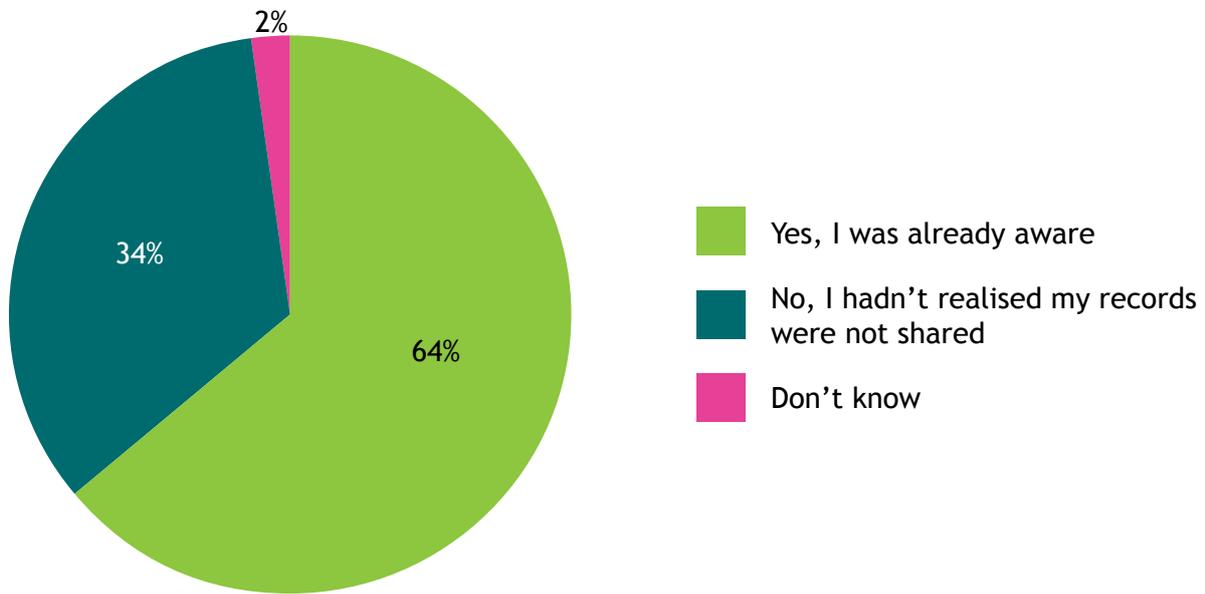
Survey:

5.1. Public awareness of record sharing prior to starting the survey.

The first question followed an introductory paragraph which explained the current situation regarding sharing of health and care records between relevant professionals involved in a person’s care, and why the survey was being carried out. Respondents were asked whether prior to reading this introductory paragraph, they had been aware that their records were not readily shared.

Over a third of respondents were not already aware that their records were not readily shared between the professionals involved in their care. This was roughly the same for both men and women. There was, however, a difference in awareness according to age, with those aged under 50 and over 80 being less aware that their records were not already readily shared.

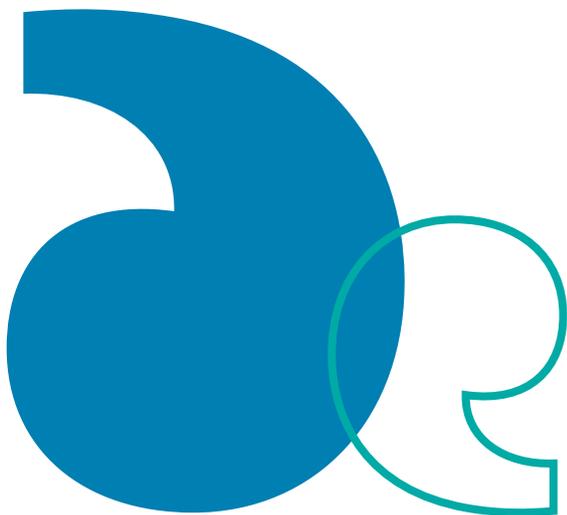
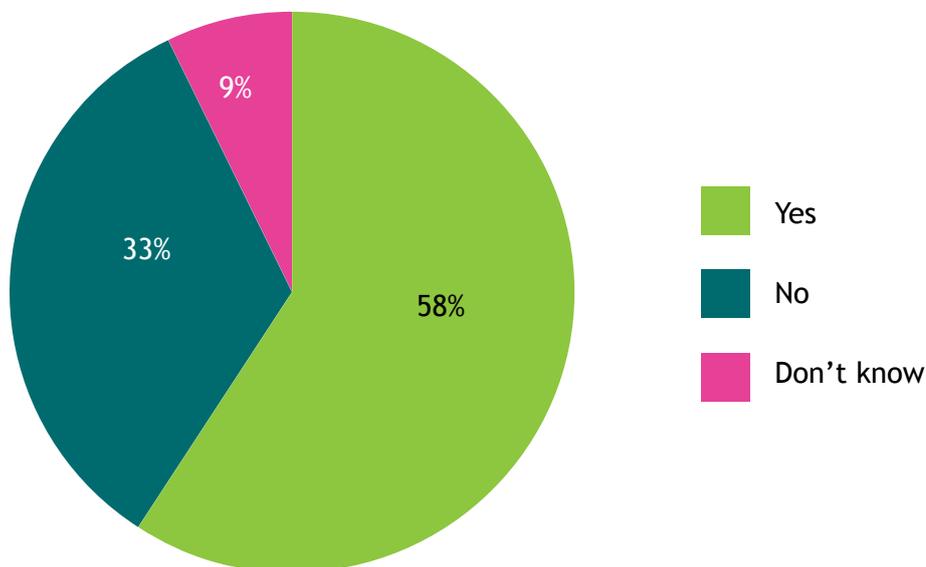
Were you already aware that your health and social care records were not readily shared between health and social care professionals?



5.2. Personal experiences of respondents with regard to records not being shared - having to repeat their story to different health and care professionals.

Previous research on integrated care has suggested that people are fed up having to repeat their story multiple times, so this was investigated to see whether it was also the experience of the public in Surrey, and an option was added to give examples of their experiences. (2)

Have you or any members of your family had any experience where you have had to repeat your story to different health and care professionals?



58% of respondents replied to say they had had experience of records not being shared, and of having to repeat their story and, of these, 273 completed the optional comment box telling us about their experience.

A sample of the comments is included over the page.

5. What did people tell us?

"When I have had hospital appointments I wonder why I am asked questions I feel they should know. It's a total waste of time. I feel time at hospital appointments is precious. If all the information is on the screen surely it aids speedier treatment."

"Both of my elderly parents (now deceased) had a wide range of medical problems requiring interaction with different areas of health care - GP, care home, hospitals. Very frustrating - repeating story each time - some still do not realise they have passed away. Appointments for outpatients still received even though both died when in NHS care."

"I was referred from GP to hospital and had to repeat everything to the consultant, radiologist, phlebotomist, nurses and oncology staff. When you are really worried about something, it is difficult to remember if you have told everyone all they need to know and whether you are repeating yourself."

"Lack of communication between discharging hospital and local surgery led to my 94 yr old father taking the wrong dose of one of his drugs, which led to serious health problems and his subsequent death. Family had to constantly repeat dad's medical history on each change of ward/hospital to ensure continuity of care."

"I have a hearing impairment can't lip read via phone I use hearing loop when available. If my GP passed this on to the hospital they would have no excuses for disabling me by assuming everything is 20/20."



"Out of hours GP did not know my drug allergies or other history."

"My father in law had dementia and was in hospital for quite a while and then went straight to a care home. He was then assigned to another GP who didn't have the records from the practice where he had been going for over 50 years and if it hadn't been for us as his advocates I dread to think of how things could have gone wrong. As it was things were not great and he was not given the full attention he would have had with his own GP."

“Son treated in hospital for serious deep wound needed plastic surgery. Took over 6 weeks to sort out between Torbay hospital Cobham GP and Royal Surrey. No sharing of records. Completely ridiculous. Also father with bipolar disorder no joined up thinking going on there either.”

“Chiropodist has to have it re explained every visit that my legs do not fully straighten due to snapping hip. This is important because of set of treatment chair.”

“Letters not arrived in time for appointment. Between Hospital / Doctor.”

“Consultant referrals not aware of any history and when you are dealing with multiple referrals it is extremely frustrating to constantly re-tell the story (especially when it's complex). Things then get missed, overlooked. It's very tiring for the family. Also consultants within the same hospital not talking to each other! On one occasion my daughter was admitted to hospital, I asked them to call her consultant in London for a full history (they didn't) so I called and the consultant told me what to tell the other consultant he wanted done! Not professional at all!”

“I have received treatment in a number of hospitals over the past decade. All were unaware that I have had my spleen removed and I am vulnerable to bacteriological infection and require daily antibiotics.”

“Outpatients department were unaware of my learning disabled care plan so left me in open waiting room.”

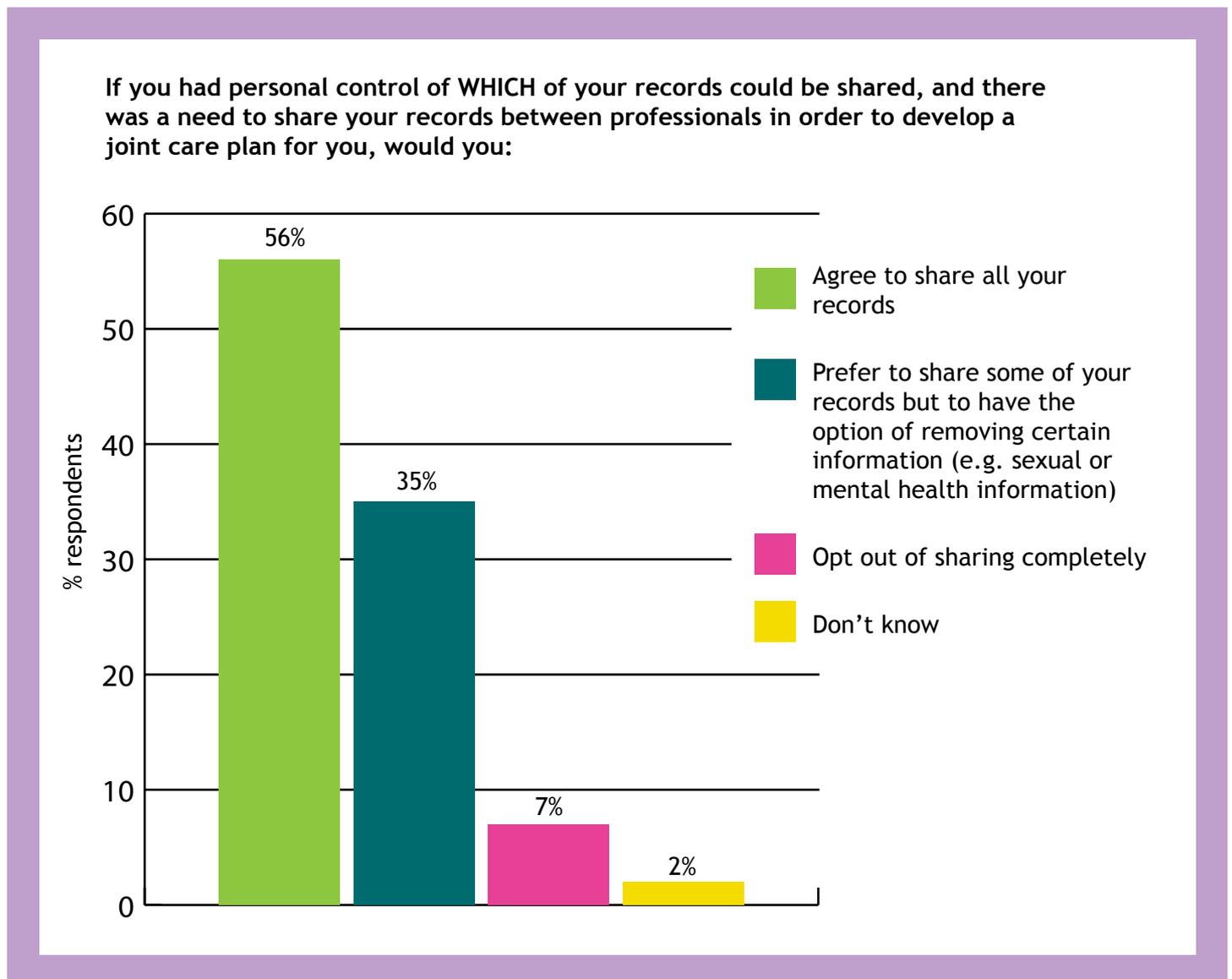
“Well I have a disability which isn't really recognised (vestibular disorder) and it would be very very useful if this was shared cos I feel like an idiot saying it each time I have a fall or recently I had a trapped nerve and it certainly impacted on my care and was part of the cause. Also if it was shared, PIP might have bothered to get more information on my case. I am too tired (and didn't know they didn't get reports) to get my reports from every health care person I have ever seen for this - neurologists, ent's balance therapists, audiology to name but a few.”



5. What did people tell us?

5.3. How much of their record are people willing to share - all, none, or just selected parts?

Only 7% of respondents would opt out of sharing altogether. 91% of people would share all or part of their records in order to support a joint care plan between the professionals involved in their care.



There was an option to tick 'other' and comment on this question. A selection of comments are opposite. Recurring concerns centred on third party access, the accuracy of the information in their records and whether it was up to date, having personal access or holding the records themselves, and distrust of social care professionals. There were also positive comments about the benefits of shared access.

Women (54%) were less likely than men (59%) to agree to share their whole record, whilst older people were more likely to agree to share 65-79 years (65%) and 80+ years (80%) than people in the 50 - 64 year age bracket (48%) or 25 - 49 years (55%).

Comments

Third party access:

Ideally I would like them shared but I do have great concern about security of the information held as I don't have great confidence in government IT systems.

I agree that sharing between NHS professionals is a great idea but I am extremely concerned about security of records.

I have opted out all together. If my health or social care records need to be shared with anyone for my benefit then I would like to be the decision maker about who needs to know. Our personal information is getting into the hands of too many people who are using it carelessly and nothing is personal anymore. Too much assumptions are made by professionals, who seemed to think they know best.

I have concerns as to whether insurance companies, employers etc would be able to access them now or in the future. Even though I have ticked the second box I am still concerned that medical advances e.g. in genetics may impact negatively on some folk with inherited condition if say insurance companies have access to these records.

I think it would be efficient for my records to be shared between different services of the NHS. However, I am worried by increasing privatisation and would not want my medical data to be available to commercial organisations in the UK or overseas.

Only with certain health professionals/distrust of social care professionals:

Doctor and hospital fine, but not sure about social workers, not sure what one is

All health professionals should have access to all records automatically in order to best treat but I would want to be able to choose which records are shared with social care professionals

I would not want care workers to have my records. Only medically qualified persons. I have seen instances of dishonesty by home care workers.

Ensuring accurate and up to date information:

And want to read them so that I could see whether what was being shared was right!

I would ensure either those professionals who needed access had it, but I would want to know the record was accurate. As a health care professional I am only too aware of the inaccuracies in records currently

I am a governor at the XX Hospital and also a scientist and I am well aware of the ongoing issues with electronic data and issues of privacy. In addition, I recently discovered that my GP was referring me to hospital consultants with an incorrect medical history which cited kidney disease (which I do not have) and other issues that were so out of date as to be irrelevant. I corrected this by paying to see (and correct) my record at the GP. However, this has made me cautious of what gets stored and passed on without my knowledge. I would prefer to personally hold my own record on a data stick which I could see and take along with me to whomever.

Benefits of shared access:

As long as the information goes between people agreeing on my care, it can only be helpful.

I have raised an Advance Directive lodged with the Doctor I would like this to be known to all.

Personal access to information:

Keep all my records myself just as they do in Europe

I don't know what they contain myself, so I wouldn't want blanket consent prior to viewing them myself.

Happy to share ALL provided that I had access to ALL. If I cannot have access to all then no-one else should.

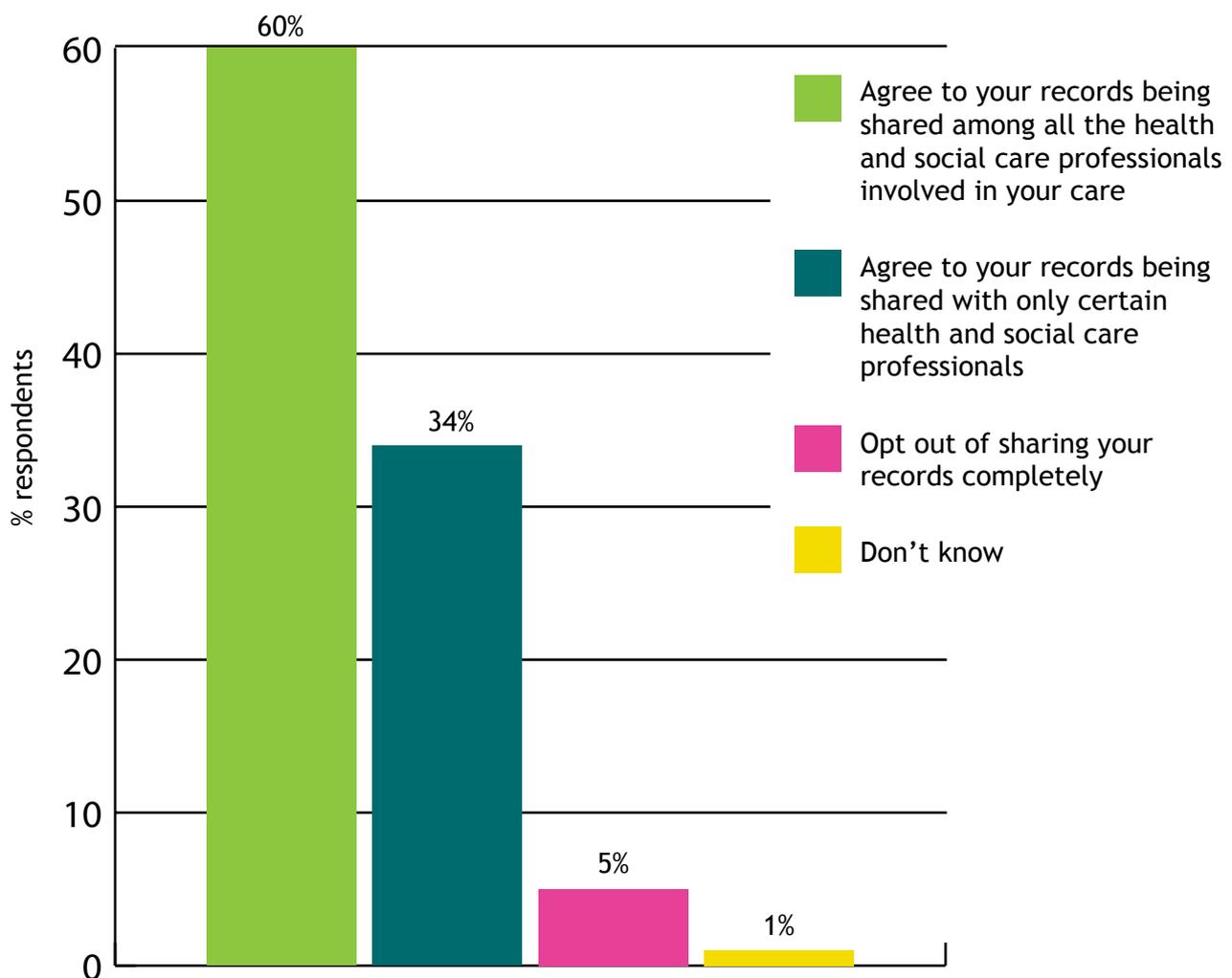
5. What did people tell us?

5.4. In general which professionals would people choose to have their records shared between - all or only selected professionals?

94% of respondents would be willing to share their records with all or some of the professionals involved in their personal care. 5% would opt out completely.

Age and gender were provided by a majority of respondents, and where the information was available further analysis was carried out. This showed that males (62%) were far more willing than females (50%) to share their records with all professionals. Well over 60% of people under 50 or over 65 would be willing to share with all professionals but this drops to 52% for the 50 to 64 age group.

If you had personal control of WHO your records could be shared with, and there was a need to share your records between professionals in order to develop a joint care plan for you, would you:



5.5. Which professionals would people be willing to share their health and care records with?

This question followed up on the previous question, investigating in more detail which health and care professionals people would be willing to have their records shared between. People could tick as many boxes as they wished.

	Yes	No	Possibly	Don't know
GP	96%	0.4%	2%	1%
Other surgery staff giving care	75%	5%	16%	1%
Hospital doctor	93%	2%	4%	1%
Other hospital medical staff giving care	69%	6%	19%	2%
Other health professionals e.g. Physiotherapists, mental health support workers, health visitors	60%	9%	24%	1%
Social worker giving care	45%	17%	26%	4%
Other care workers e.g. home care workers	30%	28%	26%	6%
Paramedic/ambulance staff	71%	7%	17%	1%
Pharmacists	41%	18%	27%	2%

There was a clear divide between the medical and social care professionals. Whilst a large majority of people would be willing to share records between GPs, hospital and other surgery staff, there was considerably less willingness (<50%) to share with social care professionals or other care workers (30%). These findings closely mirror those referenced in the GMC literature survey on attitudes to privacy of healthcare data.(3) Asked who should be able to see your medical records, a MORI poll in 2008 reported: GP - 95% said yes, hospital staff giving care - 87% yes, Social Worker giving care - 50% yes.(3)

This may in part be due to the fact that many people have less experience of social care. According to the 2014 Department of Health survey, Public Perceptions of the NHS and Social Care, *“only 31% of people surveyed say they have experienced at least one of a list of social care services in the last year or so either personally or through a member of their household, family member or friend.”* (5)

This issue came out as a theme in the optional comments boxes, where it emerged that many people were unsure of the professional status/ qualifications involved in social care, and there was a lack of knowledge surrounding their work, and in quite a few cases, a general distrust of social and care workers.

Further discussion in focus groups with over 65s confirmed the lack of knowledge around the status and qualifications but on the issue of trust there was a divide between those who registered distrust and were against sharing, and others who had often had personal contact with social care workers and were in favour of joining up health and care and sharing their records between the relevant professionals. As one participant noted,

“If integrated care is going to work it has to be integrated..... People dealing with home visits, with the district nurse... if those people cannot have the information which is shared between the doctor and the hospital .. you cannot set up a platform which prevents you from having to go to an acute hospital unless it is really necessary. Because if they have your records they can say ‘oh yes she has had three events of that sort, I think this time she ought to go to the acute’.”

Focus Group with over 65s, Godalming.

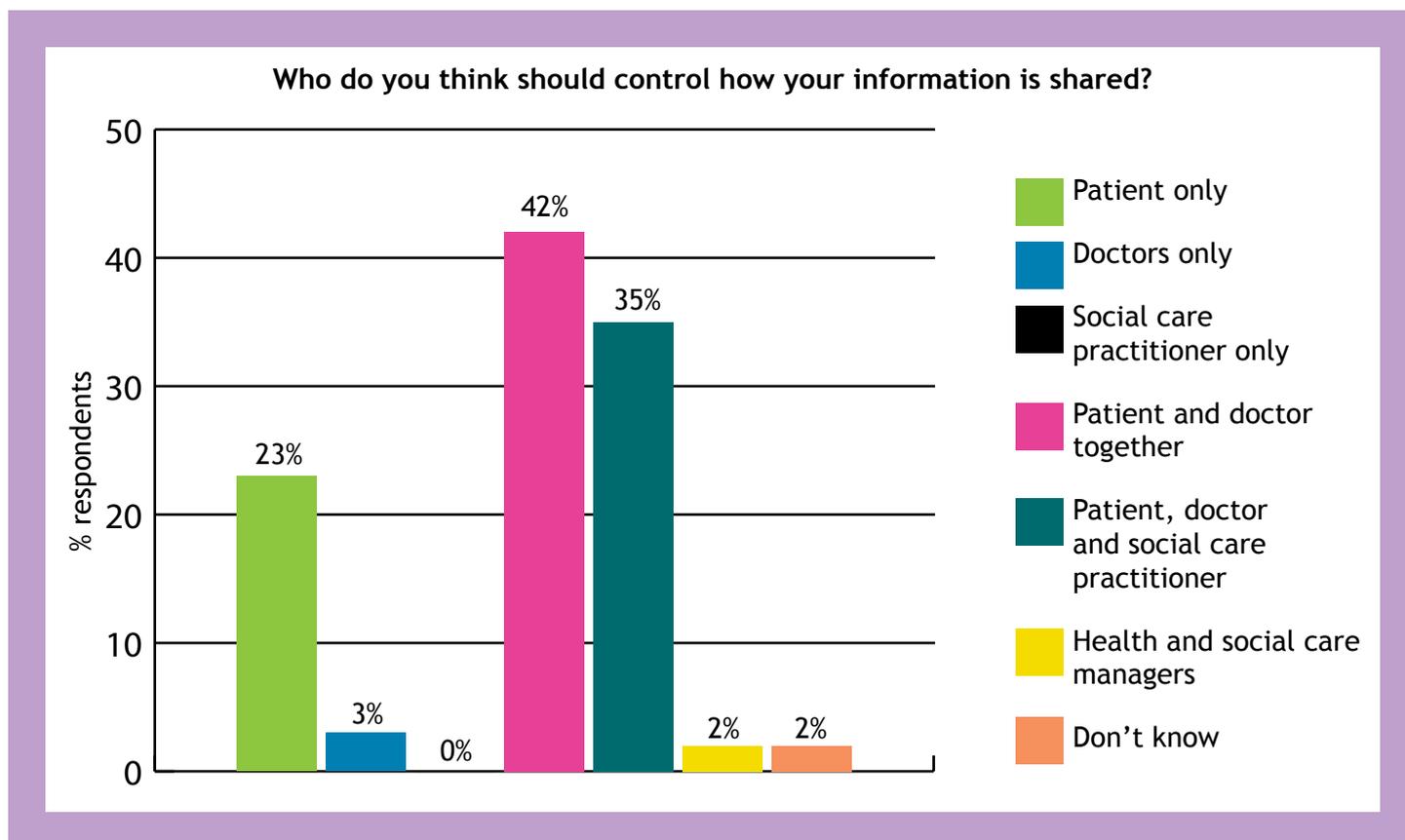
The lack of willingness to share with pharmacists was discussed within the focus groups with over 65s and in general there was a feeling that people would not consult their pharmacist instead of their GP, and there was even some indignation at being asked by pharmacists to spend two minutes reviewing their medicines: *“That is what my GP is for!”* Focus Group with over 65s, Godalming.

5. What did people tell us?

5.6. Public views on who should be involved in decisions about how their records are shared.

Asked about who should be involved in decision about how records are shared, the majority of respondents wanted a combination of the patient with a doctor (42%) or the patient, in combination with a doctor and social care practitioner (35%). 23% of respondents wanted sole control over decisions.

Some respondents ticked more than one box hence totals exceed 100%



Comments:

“Or have a policy where all records are shared with all HCP to reduce risk/errors/miscommunication”

“Default position should be share all with all, with the patient offered ‘opt out’ options”

“But I’m not sure I trust them not to use them for ‘research’”

“I don’t think it needs to be controlled by anyone, as long as they are restricted to only health/social care professionals in the public services (not private companies!!)”

*“If we still had a *National* health service, one which was publicly provided, publicly funded and publicly accountable, I would be content for my GP to share info with anyone else in the NHS - I am not content for any of my data to be shared with 3rd party companies.”*

“But like on Facebook, the patient could be in charge of allowing professionals requesting to see their records.”

“I think the patient should consent for general health care, but when it comes to emergency care the health professionals should be able to share relevant

information - not just within the NHS, but also other response agencies (police, fire, Local Authority etc).”

“I think that if there is a safe guarding issue, it should be that the doctor and/or social care practitioner can override a decision made by the patient.”

“Why not a central computer where details are stored. The banks can do it so why not the NHS”

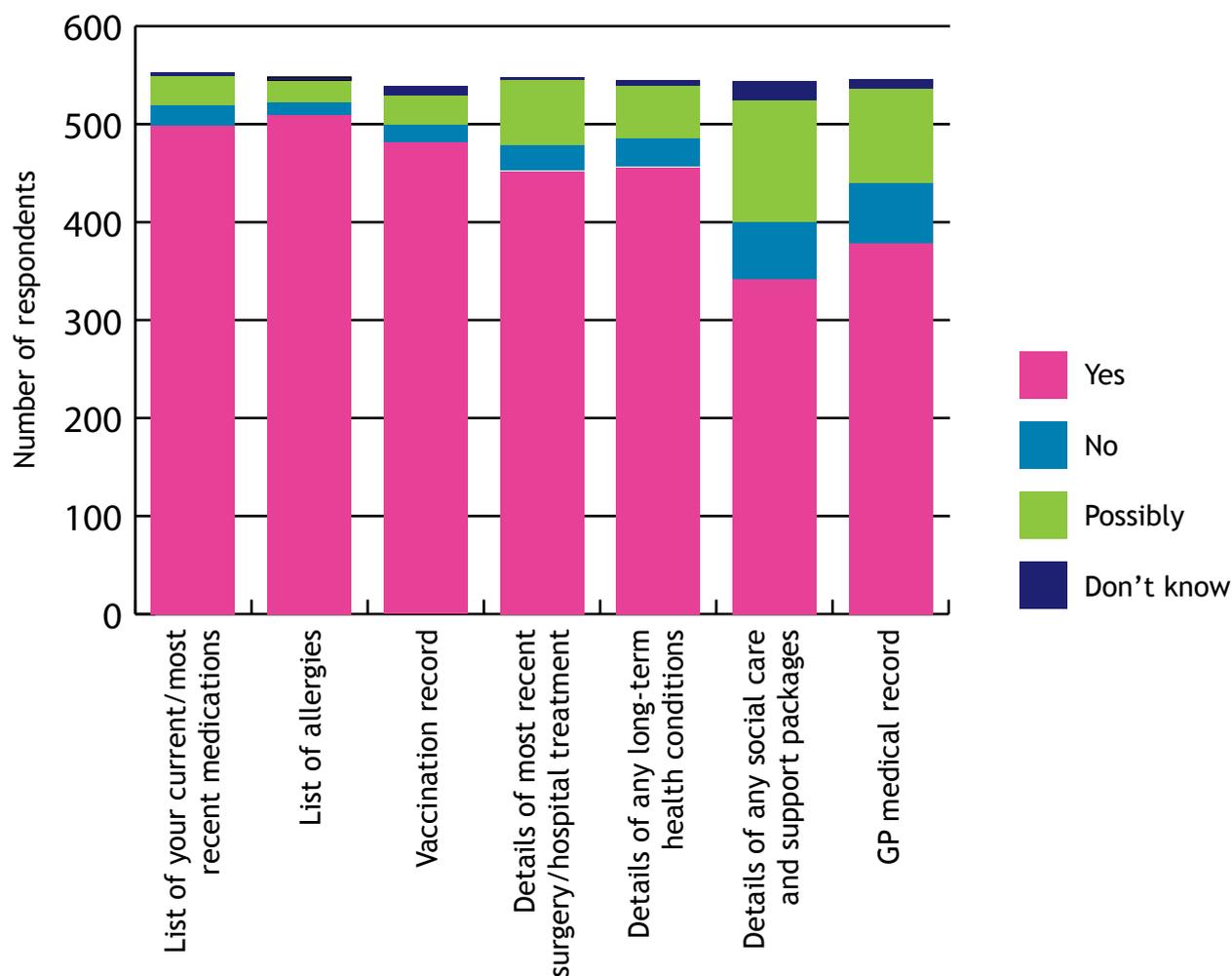
“Why does it say nothing about family or carer?”

5.7. What sorts of health and care information would people be willing to have shared?

Respondents were given a selection of types of information that could be shared between the professionals involved in their care, and asked which they would be willing to have shared.

This question provides examples of the sorts of information that could be securely shared.

Would you allow professionals involved in your care to share the following:

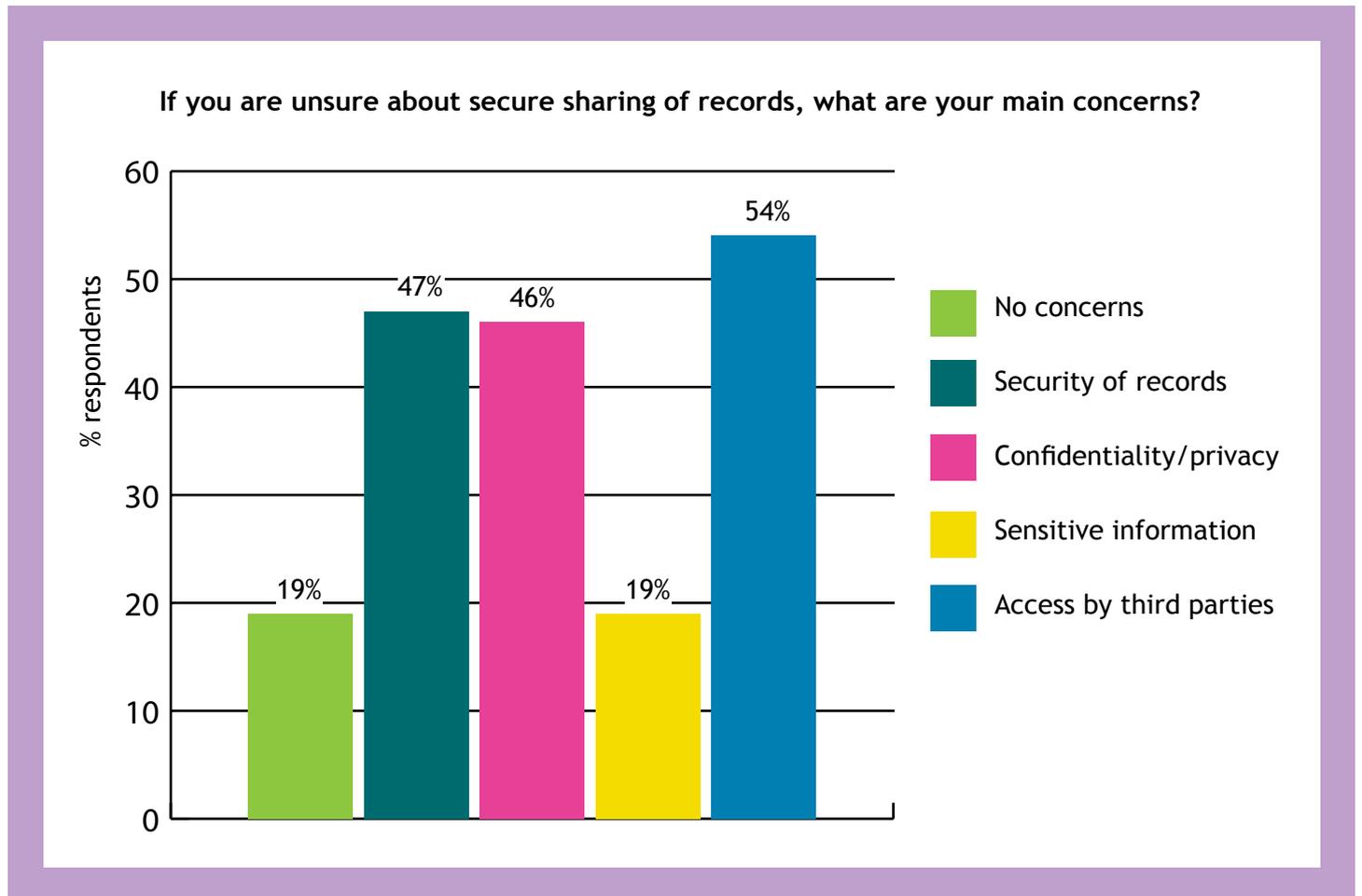


There is more support for sharing of vaccination, allergy and medication health histories than complete medical histories. There is also a larger percentage of people saying 'no' to sharing information on social care and support packages.

On further analysis however, there are fewer older respondents within this 'no' group than younger respondents, possibly due to older people having a higher level of involvement and knowledge of the care system as suggested in the focus group discussions.

5. What did people tell us?

5.8. What are the main areas of concern with respect to sharing health and care records?



People were asked to pick their top two concerns, hence percentages total 200%

The question provided an option to tick 'other' and comment. 10% ticked this as one of their two options, a selection of comments are below. The majority of concerns centre on third party access and selling of information to outside parties.

Third party access:

Insurance companies

No computer systems are secure. Companies, [insurance. banks etc,] will start to buy information and discriminate against people.

I know people who work at the hospital and wouldn't want them to be able to access my GP records.

Private companies involved in health care could easily find ways of profiting from the information; this needs to be controlled!

Selling of information

When ANY provider within the NHS is no longer truly an "NHS" provider, any such company could in theory gain access to my personal and private information. In many cases, these companies have links to, or are even owned by, healthcare insurance providers - As we are currently marching headlong towards a US style insurance based healthcare system, I absolutely refuse to allow ANY such sharing - my life may literally depend upon it.

I do not expect you to be able to control who has access to this data.

Being sold to insurance companies to increase premiums.

I worked as a temporary secretary in a local GP practice and had access to everything, abortions, alcoholism etc etc.

Reliability of computer system/backup:

My only concern would be what would happen if the computer system goes down and the information cannot be obtained

Loss/corruption of data. Inability to get mistakes corrected

Is the back-up system thoroughly reliable? What happens if the main database system goes down or becomes corrupted?

Accuracy of information:

I would be concerned that correct information is passed on. i.e that at each stage the most up to date info is passed on and hospital professionals don't assume that important data is up to date. I know how long it can take currently for example for information to be recorded on patients records and how easy it could be to pull up the wrong set of records on computerised systems.

Problem if information is inaccurate & you are unable to access it yourself/need to pay a fee to view it. Concerns about inaccurate info are not taken seriously & impossible to have corrected & this compromises care/ causes prejudice if it is allowed to spread to other services without patient knowledge or involvement

Other comments:

Means any diagnosis will be on record so doctor will not look at with fresh eyes.

People record information differently and this could lead to misinterpretation within the professions.

Happy for recent relevant information to be shared, but not my entire lifetime history as not relevant.

I do not want social services accessing any information - they are irrelevant waste of tax payers money.

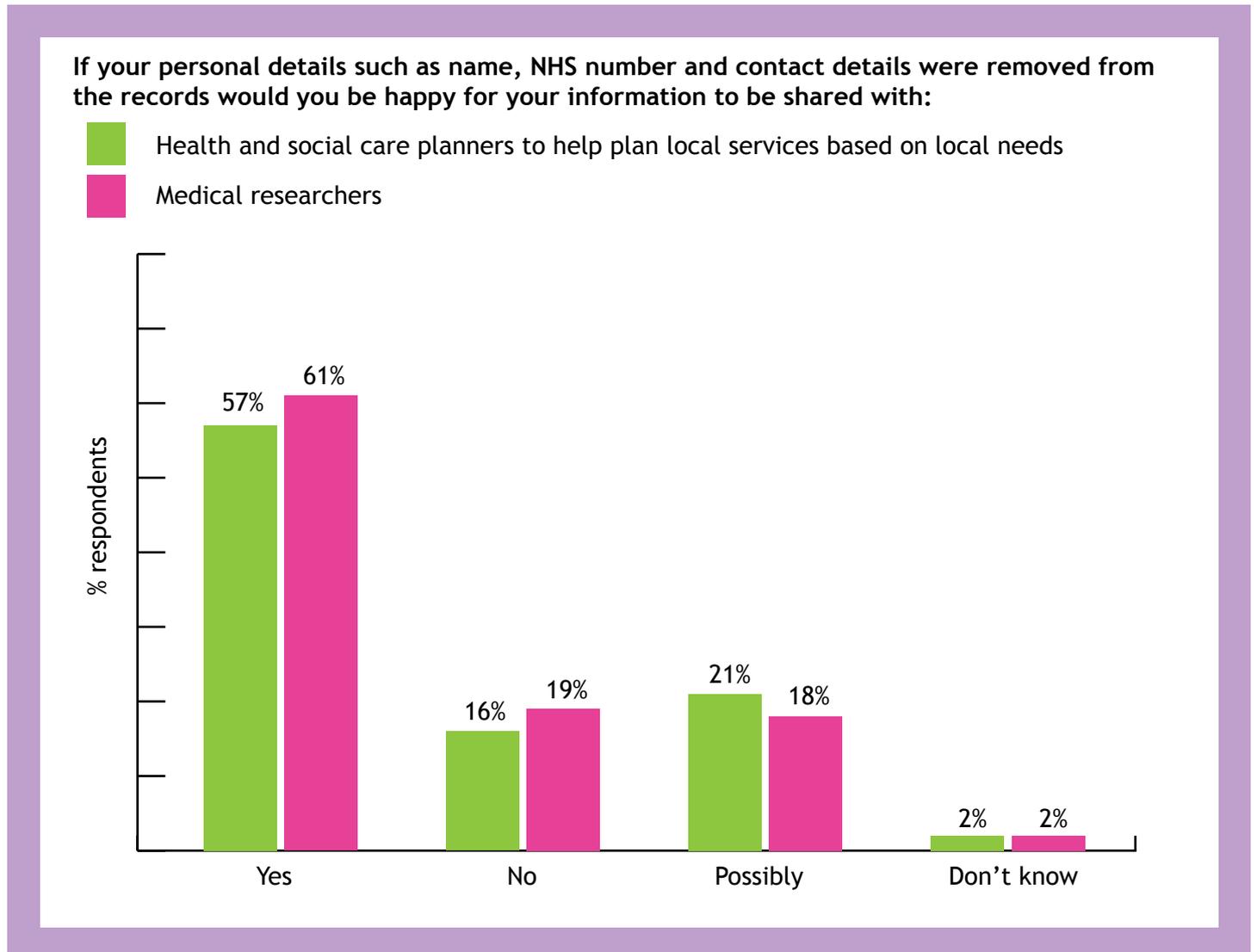
No discussion about me should take place without me. My records should not be shared with private companies.

Concerned that access should be on a need to know basis and not generally available.

5. What did people tell us?

5.9. Views on sharing anonymised records with medical researchers and health care planners.

The GMC research suggested that if people's concerns are addressed they are more willing to share even for altruistic purposes.(3) This question investigated willingness to share anonymized data for the benefit of health and care planning or medical research.

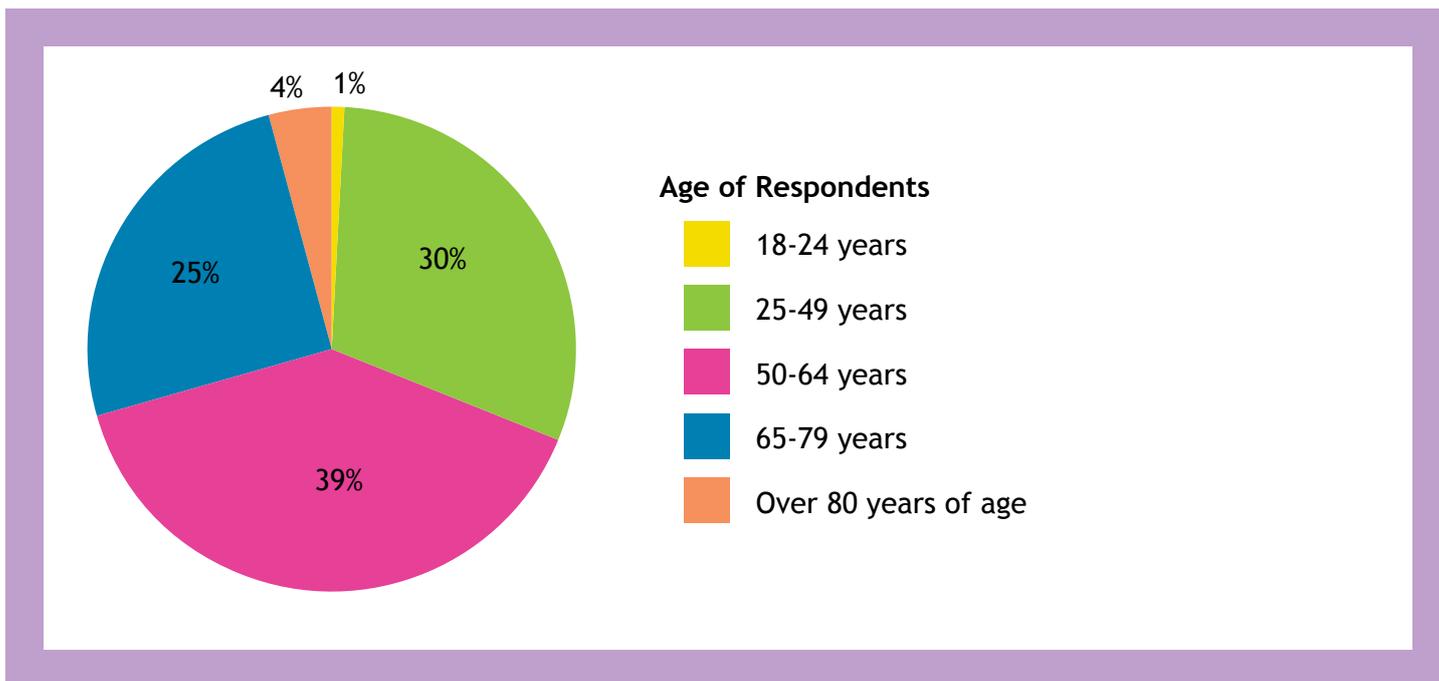


In the Mori poll referenced in the GMC review, 63% of respondents said yes to medical researchers seeing their records, and only 47% agreed to NHS managers seeing them (3). In this survey, considerably more people (57% of respondents) were willing to share with health and social care planners.

In this survey it is not clear whether the Mori poll referred to anonymized data, it is possible that the use of the term 'health and social care planners' was more informative than 'NHS managers', and also the explanation of how the information would be used served to increase willingness to share with health and social care planners in this survey.

5.10. Demographic characteristics of respondents

- 68% of respondents were female, 32% male.
- 15% of respondents considered themselves to have a disability, 85% did not. (45 skipped the question)
- 96% responses were from people who categorised themselves as White, 3% Black, 1% Mixed race, 3% ticked 'other', 52 people skipped the question.



Focus Groups:

Healthwatch Surrey were running another project at the same time as the survey, investigating access to primary care by over 65s. Four focus groups took place, and at the end of each group questions were added about record sharing.

The first group was a very IT literate group, most members had found out about the focus groups via Streetlife and all were keen on online booking and text reminders. When asked initially about record sharing, several members were vocal in their opposition and mentioned security concerns and care data, and that they had made sure their GP knew they did not wish to participate. However, another participant then spoke up and shifted the discussion when she recounted her story:

“I think that’s a shame because I watched the whole of the care.data select committee - you can go on television now and watch the whole thing... it was very interesting. But I think it was Public Health England or NHS England, they made a big cock up of it which was a shame. My daughter died of something called Reye Syndrome, and if they hadn’t collected data on that, because it is so rare, they wouldn’t have found the connection between that and aspirin. Because now you shouldn’t give aspirin to a child under 12, it’s virtually disappeared.”

Focus group with over 65s, Leatherhead.

5. What did people tell us?

The second focus group with over 65s was of quite a different composition. Only one person had a computer which she rarely used and didn't like online booking, only two had mobile phones, and none of them drove any more. There was strong support for sharing records as this group struggled to remember all their medications and repeat them when they saw different professionals, which in turn led to anxiety that they were forgetting to mention important details.

One participant mentioned that she had a 'message in a bottle' in her fridge with all her necessary details, with a green sticker on the fridge door and another on the light switch nearest the front door for the paramedics to find when they entered the house. She had also taken a copy of this and kept it in her handbag to show to any health staff she sees, or for someone to find if she gets taken to hospital, as she finds it difficult to remember all the different medications. Before her husband passed away, he had to visit hospital frequently, often via the 999 service, and she kept a book with details of all his medications and his doctor and hospital visits, as it was too complex to remember and repeat every time. Several other participants were taken with this idea and said they would like to do the same as they find it difficult to remember all the necessary information every time.

They also mentioned family members with dementia who were unable to recall all their personal health details. There was strong support for record sharing from this group to make it easier so that they didn't have to write things down and keep repeating themselves.

A third group, men only, drivers, mobile phone and internet users, had mixed views. Most were in favour but with some reservations according to professions - they were happy with medical staff - doctors, other health staff, paramedics sharing their health records, but much more wary of sharing with care professionals. Some did not want any sort of sharing beyond medical staff.

*"I'm quite happy with the medical profession seeing it, ... As long as they don't share it"
What is the training level of these social care workers?"*

Focus Group with over 65s, Ash.

However, in the last group there was more support for sharing with social care professionals, provided security issues were addressed. As one participant responded, how can integrated care work if the health and care system are not truly integrated, and if there is to be increased care and support provided in the community then it is essential that the health and care services talk to each other and share information otherwise it will be unworkable.





6. 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.

During the survey, when the limits of the sharing were clear, the vast majority of people were in favour of sharing, but when the discussion took off on its own, for example on Streetlife or Facebook and even in the focus groups and at engagement events, it frequently and quite quickly moved to concerns about third party access - insurance companies, private companies, family members. Having to constantly explain the boundaries of the sharing, led to a few negative comments that the survey was biased, that one point of view was being promoted. However if these limits were not promoted, anxiety about third party access would resurface. It is important that this consideration is kept to the fore when taking this work forward.

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 their records.

There was a marked divide between willingness to share between medical/health professionals where support was strong, particularly between GPs and hospital doctors, and willingness to share with social care professionals such as social workers and home care workers, where agreement was provided by less than half of the respondents.

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 have had less personal experience upon which to base their views,

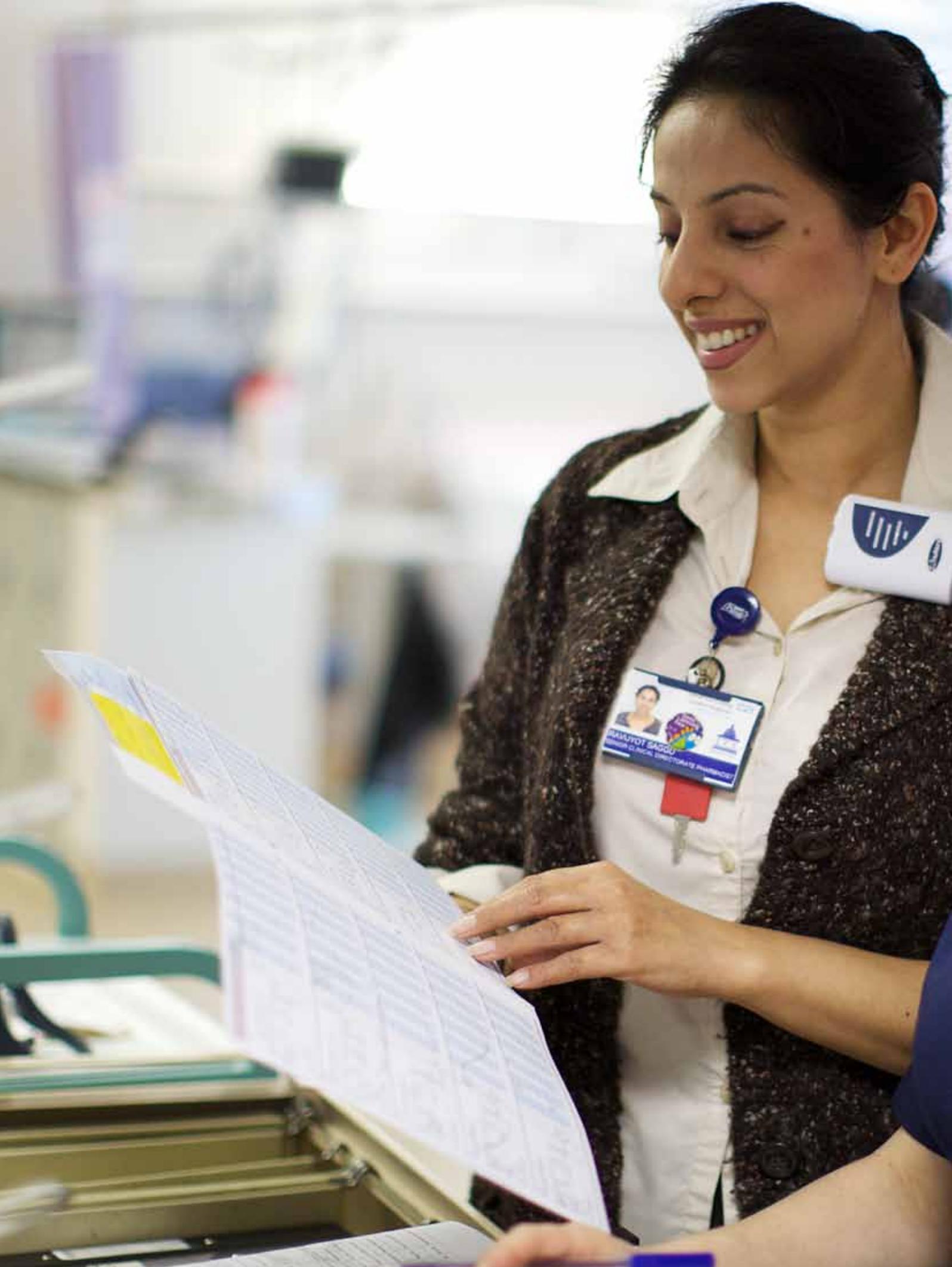
but it also suggests that there is a need for more explanation and reassurance around the roles and work of social care professionals in general.

Amongst older people who had had more contact with social care professionals there was more understanding of their role and the benefits of sharing.

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 and this was born out during focus groups with over 65s where 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 everytime they saw a health professional, or of having to keep a written list as some currently do.

If personal identifiable details are 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.





Healthwatch Surrey will deliver the report to Surrey County Council to inform future work on integrated care and will also be raising awareness of the findings with the following individuals, groups and organisations:

- ✓ Members of User Involvement Groups (e.g. Patient Participation Groups)
- ✓ Surrey Health and Wellbeing Board
- ✓ Surrey Transformation Board
- ✓ Surrey Information Governance Group
- ✓ Local Joint Integrated Commissioning Groups
- ✓ Wellbeing and Health Scrutiny Committee
- ✓ Department of Health: National Information Board
- ✓ Healthwatch England
- ✓ Local Government Association



8.

Contacting Healthwatch Surrey

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@healthwatchsurrey.co.uk
-  Website: www.healthwatchsurrey.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
-  Text (SMS): 07561 392818
-  Email: advocacy@healthwatchsurrey.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:

 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



References

1. NHS England Publication Gateway Reference Number: 00076. <http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>. <http://www.nationalvoices.org.uk/>. [Online] March 2013.
2. King J, Gibbons E, Graham C and Walsh J. http://www.pickereurope.org/wp-content/uploads/2014/10/Developing-measures-of-IC-report_final_SMALL.pdf. www.pickereurope.org. [Online] October 2013.
3. Cambridge Health Informatics . http://www.gmc-uk.org/GMC_Privacy_Attitudes_Final_Report_with_Addendum.pdf_34090707.pdf. www.gmc-uk.org. [Online] November 2007.
4. 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. [Online] October 1, 2015. [Cited: October 9, 2015.]
5. IPSOS Mori Social Research Institute. <https://www.ipsos-mori.com/researchpublications/publications/1747/Public-Perceptions-of-the-NHS-and-Social-Care-Survey.aspx>. www.ipsos-mori.com. [Online] January 2015.





Appendix 1: Survey distribution

The survey was distributed via various channels:

- Embedded on the Healthwatch Surrey (HWS) website
- Sent as a link in the HWS e-Bulletin to all on the HW Surrey database
- Sent as a link to the HWS Voice network
- Sent to all the Citizens Advice Bureaux in Surrey and further promoted by HWS Champions in each bureau e.g. to outreach groups, Community and Voluntary Service (CVS).
- Sent to Surrey Hubs
- Sent to Surrey Youth Focus and included in their bulletin
- Sent to Surrey Minority Ethnic Forum and further promoted by their researcher
- Hard copies and email link sent to Lockwood Day Centre
- Hard copies and online links handed out at engagement events -
 - Action for Carers conference, Denbies, 9 June,
 - Surrey Special Educational Needs and Disability conference (SEND) conference, 11 June,
 - Surrey Independent Living Council (SILC) Fair, Epsom, 25 June,
 - Armed Forces Day, Guildford, 27 June,
 - East Surrey Hospital, July,
 - Redhill High Street, July



- Promoted via Twitter, Facebook, and Surrey-wide posting on Streetlife
- Sent to VP Welfare and Campus Officers at higher education establishments in Surrey (Royal Holloway, University of the Creative Arts, University of Surrey)
- Press release Surrey-wide, picked up by Epsom Guardian (online) and Surrey Advertiser (print)
- Radio interview with Radio Surrey discussing the survey, and how to access it
- Hard copies taken and completed at Mytchett Children's Centre
- Hard copies taken and completed at Haslemere Health Centre
- Sent to Health and Wellbeing Board Communications Group (led to inclusion in Surrey Downs Clinical Commissioning Group (SDCCG) Newsletter and Central Surrey Health co-owner (staff) newsletter) Also on Healthy Surrey and SDCCG website,
- Sent to HW Surrey volunteers who helped distribute and complete at engagement events and forwarded to family and friends
- Sent to Joint Commissioning Manager Health & Social Care North East Hampshire & Farnham Clinical Commissioning Group / Surrey County Council who forwarded to the Communications team at the CCG, Patient Participation Groups, GP practice managers and Farnham networks.
- Sent via Surrey County Council to Surrey Information and Governance Group for forwarding to their respective organisations
- In addition the subject was discussed during four focus groups for another HWS project on access to primary care for over 65s in Leatherhead, Oxted, Ash and Godalming.



Appendix 2: Distribution of responses across Surrey by postcode

500 respondents provided the first digits of their postcode. The heat map below shows the distribution of responses across Surrey. Note postcodes do not match exactly to the county boundary, and some postcodes around the periphery are outside Surrey.

Additional views were provided in focus groups for people aged over 65 in Leatherhead KT22, Oxted RH8, Ash GU12 and Godalming GU7.

