

Citizen Insights to inform the content of Surrey Care Record (SyCR) Public Information Video and Communications.

Introduction

The SyCR (Surrey Care Record) is a local, digital shared care record for health and care professionals across Surrey Heartlands. It allows the secure sharing of patient health and care data between authorised health and care professionals for the purposes of delivering safer, quicker, and more coordinated local health and care services.

The team commissioned a research project to gather insight to inform the production of a short public information video. This will form part of a wider multi-media SyCR education campaign aimed at sharing the anticipated benefit of care record sharing for patients. To deliver a relevant and impactful video, it is important to understand where patients feel that their current health and care experiences could be improved and target these key areas in the context of efficient record sharing.

Aims and objectives

- To gauge the current level of public understanding of sharing care records and of the SyCR programme.
- To identify themes in patient stories which could be impacted by record sharing.
- To understand where patients felt that their care experience may have been impacted by information sharing.
- To gather any possible concerns patients may have over information sharing.
- To better understand how we can build patient trust through the content, quality, and style of SyCR public communications.

Summary and key themes

Although this work was intended to inform the development of the SyCR public communications, the insights provided went far beyond this scope. The interviewees had such vast family medical histories that they shared a wealth of experiences, including record sharing and the use of digital tools to enable optimum care for complex, chronic health conditions. These patient stories are worthy of a wider audience.

Some of the key themes shared by these patients were:

- There is a poor understanding of the current meaning and use of 'Shared Care Records' even amongst families with complex, chronic health needs.
- The current sharing of medical information is very inefficient, and this has a huge negative impact on the patient's healthcare experiences. There is a perception that a lack of record sharing can even mean that critical decisions are delayed because the information is not available to hand.
- There appears to be no cohesion amongst care and therapy teams even within the same medical team and the situation is worse moving from child to adult services.
- COVID has enabled online consultations which reduced the stress of appointments. It should not be necessary to have to travel for tests, scans and consultations which do not involve physical examinations.

- The key concerns for Shared Care Records were around confidentiality, the quality, and the context of the information so that assurances are needed that the right people are reading the information.
- There was a view that patients want the professionals to have the information they need to provide the best care for them and that people with chronic multiple conditions already understand the value of it.

Recruitment

Recruitment for this research presented challenges due to lockdown. Invitations to participate were shared through personal contacts, Healthwatch Surrey social media channels and third-party organisations by email and phone call. Of the latter, a total of 16 groups were contacted in an effort to capture the diverse demographic of Surrey Heartlands residents, for example, elderly, BAME, learning difficulties, faith, youth, family and mental health charities and organisations. These groups then shared with their patrons through their online forums such as social media and newsletters. Unfortunately, the response rate was very low.

Three citizens, all a similar demographic (namely, white British middle aged female carers), were interviewed by remote video each lasting approximately 1 hour. All three were carers for family members with complex, chronic health conditions so that they all had experience of multiple health and social care and therapy settings.

Research questions

The interviews were structured around the objectives but were informal to allow the interviewees to draw on their own personal experiences.

Insights

1. *Digital attitudes and capabilities*

All interviewees were both digitally enabled and literate with a positive attitude towards lifestyle and healthcare digital technologies.

2. *Understanding of sharing care records and of the SyCR programme*

In response to the question regarding their understanding of the term 'health and care records', the responses ranged from "not a lot" to a very good awareness. Suggestions were that it referred to:

"Any contact I have had with a hospital or doctor, consultant reports, and any interventions including blood and other test results"

"Looking up your own health records and querying if medical records link with other health professionals (e.g., dentist)"

"All the care comes under the NHS, but all the records are very separate. The medical records (that the patient can see, at least) do not reflect the complexity of the condition and are very misleading due to the limited information there."

Other thoughts were that most information is local professional knowledge built through the family relationship with their trusted GP and that this depth is not currently captured in health and care records.

Respondents understanding of the term 'shared care record' included that it is a record that someone can see but not alter, that is, not a review and edit record whilst it was also described as:

“A holistic view so that different healthcare providers can access my records.”

Their understanding of how health and care records are currently shared amongst professionals included that it would be by request and by email. Another interviewee was very pleased to hear that this project was happening stating that, in her experience:

“Information sharing is a joke”

“No-one owns the sharing”

Some examples of the uncertainty around current sharing of information included a question regarding carer status: does the GP see that the respondent is not only the primary carer for a son with autism at home but also a secondary carer for an elderly, dementia parent in a different county? This has a huge impact on her family life and general well-being.

In another case involving an emergency hospital visit (sent to A&E by GP), the health professional did not read the referral note in detail. Instead, they asked the mother (carer) to explain the situation and she was unsure if this was a test of recall and perspective or just poor record keeping. This created a lot of pressure on the mother (carer) as she was aware that she was the one person with the details of the whole story. She was concerned that she may missed important details. Her comment here was that:

“Standard format of records would make retrieving information more efficient for the health professionals involved. Referral letters and records sent with them vary hugely. Need consistent, quality data to have all the information.”

Interestingly, despite their vast healthcare experiences, not one of the interviewees has heard of the SyCR which may be useful to know when benchmarking the public communications efforts.

3. Patient stories

Interviewees were asked if they felt that their treatment had been impacted by information sharing and some compelling insight and experiences were shared.

In one case, the challenge was sharing oncology medical information with an elderly parent who is almost deaf and has a low level of medical literacy. The consultation reports were sent to the GP, copying the patient up to 4 weeks later using medical terms that the family do not understand. The information was overwhelming without historical context. In this case it was suggested that:

“Real time access for the carer to online patient letters would have decreased anxiety as I could have informed myself before speaking to father-in-law: I needed previous test results to reassure him. This is about the carer having oversight of the care.”

Another interviewee whose young child needs regular head measurements due to a life-threatening brain condition explained that this critical information is recorded in the ‘red book’ by the health visitor, but the parents are then expected to share this vital information with the child’s consultant. It was also noted that different tape measures are used for each recording so there is no consistency for such critical measurement. The interviewee suggested a standard operating procedure to go on a shared care record alongside the recorded results. It was also suggested that a “real time app” for parents to share the data which can be seen immediately by all health care professionals involved would be of huge benefit. In their view:

***“Critical life-threatening decisions are always delayed because the information isn’t available to hand so that:
Actions are either too cautious: GPs/health visitors want to wait for information from specialist hospitals and consultants or
Actions are too risky: They think they know enough but mum has to fill them in – leads to difficult parent/healthcare relationship.”***

In another, incredibly complex case, the patient is under the care of 11 different consultants at many tertiary hospitals in London for a complex, chronic condition affecting multiple organs and with huge psychological impact. Every medical appointment (on average, monthly) takes a whole day when travel time and waiting time is included (consultants often very late for appointments). The patient’s father takes a day off work for each appointment. The patient suffers from “functional neurological disorder” because of NHS trauma from the many hospital experiences, so her mum shared that:

“online care has been so much better especially as most appointments do not involve a physical examination”.

For example, patient was told she needed rehabilitation support at a London hospital, but she could not travel due to the trauma and there was a waiting list of over a year for this face-to-face service. She was given the chance to ‘attend’ on-line because of lockdown. This would never have happened without COVID. Moving other services online has also really helped (e.g., occupational therapy, physio- and psycho- therapy, and consultant appointments).

Other examples and experiences of record sharing impacting healthcare experiences were:

“No cohesion amongst care and therapy teams and even within the same medical team treating a certain condition. The situation is worse since moving to adult services. (Patient) has a ‘continuing health care team’ but they do not have access to any medical records.”

“(Patient) is under various teams for the same issue at different centres but there is no communication between them. For example,

(patient's) consultant moved to new hospital and (patient) was not transferred with her and was discharged from the old hospital."

Another carer reported that the patient was seen at A&E but the neurologist in London had not seen the notes which GP had sent ahead because the letters had been lost.

Interviewees were also asked for examples when they feel that their care experience may have been improved with more efficient information sharing. In one case, a carer shared that:

"The transition from teen to adult care was terrible and very frightening. (Patient) was transferred to the care of different hospitals and consultants but there was no record transfer."

She also commented that the (adult) patient is lucky to have her parents managing her case as she is too ill to do it herself and she needs individualised care. Mum carries all the patient information which puts a huge pressure on her. She advocates and speaks for her (adult) daughter. It was suggested that families try to have scans done locally to avoid the trauma of travel, but these are not shared with the tertiary centres and noted that:

"It should not be necessary to have to travel and doctors do not seem to understand how frustrating it is for these families."

Another respondent told of an occasion when a Patient was "blue lighted" to a London hospital following treatment at a private hospital and neither hospital had access to the patient's records with near fatal consequences. The initial treatment would not have been undertaken if full medical history had been known.

In another story, the interviewee's elderly mother (carer) called 111 for her husband who has dementia but she herself was also unwell. The doctor who had visited in response to the initial 111 call was concerned for her health, but he could not access records as he had come prepared to see her husband. The interviewee then had to ring 111 again for her mother and repeat the questioning that she had answered with the doctor already in the house. This angered and frustrated her at a very difficult time. Poor communication and lack of access to medical record resulted in more patient distress.

When asked for an example of an occasion when efficient information sharing amongst professionals contributed to a positive care experience, one interviewee responded that she had no positive experiences to share. She did, however, feel that she has recently seen "some moves in the right direction". For example, the patient's catheter nurse now shares message between GP, nurse, and neurologist with the patient which she values. The patient's GP has also set up a link whereby letters are shared with all consultants cf. a group chat and a London rehabilitation centre has helped parents to create a 'hospital passport' to carry to hand out to in acute emergency situations.

There were also positive experiences of information sharing reported. For example, in an acute situation, when a child became ill whilst away on a family holiday. The hospital was quiet at the time and they were very thorough in obtaining all relevant records (rang GP). There was also a very efficient onward transfer to a local hospital near home.

Another interviewee reported that she has seen an improvement in information sharing more recently within CAMHS:

“The psychiatrists/psychologists prepared great handovers and briefings, and the therapist also liaised brilliantly with psychiatrist.”

4. *Sharing public information about SyCR*

Interviewees were asked what information you would like to hear about the Surrey Care Record and the themes that emerged were around putting the patient first, context, quality, and confidentiality. For example, one interviewee asked, “how do you plan to protect my data and ensure confidentiality is maintained?” stating that she was worried about the consequences at work if sensitive information was compromised.

Another commented that:

“I don’t want to know how the records work. I want to know how it impacts our treatment – why, why, why? What is the benefit to me? Put the patient first. We want professionals to have the information they need to provide the best care for us.”

We asked how they would like to receive information about the SyCR, and the consensus was a preference for brief videos and to avoid leaflets and newsletters. One interviewee felt that updated would be necessary as the system evolved whereas another said that she is a “very busy mum so would rather have one large information package than receive constant updates.”

5. *Building trust*

There were a range of concerns and suggestion offered around building patient trust in a shared care record system. For example, one interviewee felt that:

“Sharing information is good so long as definition of terms (e.g., self-harm) is universally understood.”

From her personal experience, some terms can trigger unhelpful responses in other agencies so whoever sees the data needs to be trained to understand the information if they are going to be acting on it: ***“Jargon can be dangerous.”*** She compared it to sharing on social media in that her concern was that you do not know who will read what once it has been put on there. She would, however, feel comfortable with sharing info with other 3rd party stakeholders (e.g., charity therapy and support groups) as she feels that they understand the journey and have more empathy for the situation.

There were also concerns about the length of time for which records may be held, for example, mental health records were described as “time-critical”. She felt that data held for too long can cloud current diagnosis decisions and you can be ‘put in a box’ e.g., example labelled ‘anxious mother’ because a box was ticked when a sick child was in hospital. It was felt that is critical that the quality of information gathered and held is of a high standard, is relevant and is presented in

context. It was also suggested that binary data can be misleading because it does not allow information to be contextualised and there should be free text capture for online reports for this reason. It is also important to explain to patients why they are being asked questions e.g., a question such as 'are you anxious?' when your child is in hospital - where will that information end up and how will it be used?

Another interviewee felt that it was essential to share information and had no concerns at all because ***"we trust the right people are reading the information"***. She suggested that, for the majority, there will not be much information to share and ***"people with chronic multiple conditions already understand the value of it."***

To conclude, a quote taken from this research which sums it up perfectly:

"I Would hope that more information would make the patient 'a person' and knowing more about the whole person is more beneficial for the patient."

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