International Foundation for Integrated Care

IFIC ANNUAL SURVEY 2025

Connecting Care Information

Are shared electronic records the key to overcoming fragmentation?

Lead and Corresponding Author:
Niamh Lennox-Chhugani

Contributing Authors:
Arturo Alvarez-Rosete, Edelweiss Aldasaro, Alejandro Gil Salmerón

Contents

Introduction	3
Findings	6
Conclusions	17
References	18
Appendix 1: Focus group design	20

Introduction

The International Foundation for Integrated Care (IFIC) launched the findings of its first Annual Survey in 2022. In this and every Annual Survey since, respondents have raised the very real challenge of fragmented information and the absence of shared electronic care records (SECRs).

We wanted to understand in more detail how people are experiencing the use of SECRs in different countries and how they are contributing to an experience of greater care coordination and continuity.

What do we mean by shared electronic care records?

A shared electronic care record is a secure, a digitally-connected environment that brings together all a person's health and care records so that authorised users can access them quickly and conveniently. Authorised users, including health and care workers, the person themselves and sometimes informal carers, can read, contribute to and share those records according to their individual permissions.

IFIC's 9 Pillars of Integrated Care emphasises how information and insight needs to flow across all levels of a health and care system to enable informed action[1]. This is a theme that comes up every year in our Annual Survey of Integrated Care, now in its fourth year. People who use health and care services as well as health and care workers stress the importance of SECRs in coordinating care and ensuring continuity.

Information professionals call this kind of use of information primary use of data. This means that a person's health and care information is used directly to make decisions about their treatment and to deliver their care. This was the focus of the Annual Survey of Integrated Care this year. Another use is called secondary use of data. This is where data is used by planners and policymakers across a whole population to understand how they need to join up care better across a system. This is important as an enabler of integrated care, but not a direct focus of this Annual Survey.

[1] People at the centre of care, informal carers, health and care workers, service managers, local and national policymakers, researchers.

How do shared electronic care records help improve the experience of integrated care?

We know that information and insight enable integration at every level of the health and care system.[2-4]

In the delivery of care to people, SECRs enable members of the care team to get involved in at least five shared responsibilities. These responsibilities involve the need to: plan care together, understand the wider determinants of health that are factors in people's wellbeing, avoid duplicating care and manage treatment risks such as prescribing errors[5], improve the quality of care, and enable coordination and continuity of care.[6] While people have concerns about privacy, people want information about their health to be shared if it supports their care.[7,8] As one person put it when replying to our Annual Survey in 2022:

> "As a patient, when I think of integrated care, I think of **all my health providers being aware of my health issues and working towards my values and goals of care**. That would mean an integrated health record that is associated with me like a social insurance number, and all my health providers have access to key points about my health and care history. It means improved healthcare because there is **more communication and transparency**. It means **I won't be lost in "gaps of care"** because of the nature of the model."

For providers working together to deliver integrated care across organisational boundaries, SECRs are important. The records need to be interoperable with legacy systems and create the conditions for inter-disciplinary teams to work effectively together. This can work in two ways. Where inter-disciplinary teams meet and care teams are able to work together, information can be captured in real-time in SECRs. As in-person meetings are not always possible, as an alternative, SECRs that are supported through integrated collaboration tools[9] can support communication when health and care workers are not working with people at the same time. These two complementary uses of information for care contributes to care coordination and continuity across primary care and hospital care at a minimum and can also be extended to social care and voluntary sector providers in more mature systems. As one health and care provider put in response to the Annual Survey in 2023:

> "Whilst I think that locally in my area **integrated health care has improved significantly** as a result of introducing an **electronic, community patient record that is visible to primary care colleagues**, care still remains **fragmented** with "hand offs" from one service to another."

The question posed by the Annual Survey of Integrated Care 2025

Across all three years we have been conducting the Annual Survey of Integrated Care, the importance of shared care records in enabling care coordination and continuity in complex and pressured systems, has been stated over and over again. The question we asked in the Annual Survey 2025 was:

> Are shared electronic care records having a positive impact on people's experience of care coordination and continuity where they are in place? How do they change the way care teams are able to work together?

Methods

We changed our approach to data collection slightly this year in response to feedback from participants in previous Annual Surveys and to explore the topic in richer detail.

We conducted a short survey, open to anyone who had access to a link shared via our network. The survey asked people to share their lived experience of SECRs. At the end of the survey, they were asked to share their contact details if they wished to participate in a follow-up online focus group.

The IFIC team convened seven focus groups to explore the themes arising from the survey in more detail. Appendix 1 provides more detail on the focus group design.

When undertaking the analysis of the collected data, we clustered respondents into four groups:

1. **People at the centre of care and informal carers**
2. **Providers**
3. **Policymakers**
4. **Researchers**

There were 139 responses to the survey over eight weeks. After cleaning, 136 survey responses were analysed using descriptive statistics for the quantitative responses. Free text responses were coded inductively (codes are developed directly from the data rather than a predetermined coding framework).

22 participants took part in the focus groups. The transcriptions from all seven focus groups were cleaned and uploaded to MAXQDA for qualitative analysis. Two rounds of coding were undertaken by a team of four researchers. The first round of coding was descriptive, identifying general topics in the data largely aligned to the topic guide used for the focus groups. The second round was more interpretive, refining the round one codes, adding detail and identifying potential relationships between codes. A final round of data coding further refined and analysed the codes and proposed the theoretical framework that was used in data synthesis to provide a further level of interpretation.

Findings

Survey responses

1. People at the centre of care

We asked people at the centre of care and informal carers if the health and care workers they interact with have access to SECRs and 59 per cent of them said this was the case always or most of the time. Fewer, 48 per cent, experienced these records being shared across organisational boundaries.

Of those who did experience records shared across organisational boundaries, 79 per cent said this led to better care coordination. The reasons they gave for this better experience of coordination included:

1. Better communication between professionals
2. Greater clarity for them as the person at the centre of care
3. Better experience of joined up care
4. Involvement in decision-making and more agency
5. Reduced duplication including being asked for the same information by different providers

> "In my experience using healthcare services, I've definitely benefited from shared electronic care records. When speaking with healthcare professionals, particularly my GP or a specialist, it's clear that having access to my medical history enables them to provide more efficient and effective care. It also helps avoid inconsistencies and ensures better continuity in the follow-up"
>
> **Person at the centre of care**

2. Providers

This group included health and social care workers and service managers in the public, private, for-profit and the not-for-profit sectors. 76 per cent the providers said they had access to SECRs always or most of the time but only 46 per cent experienced these as being shared across organisational boundaries.

Of those who did experience records shared across organisational boundaries, 96 per cent said this led to better experience of coordinating care and providing continuity. The reasons they gave for this included:

1. Better communication between professionals
2. Which leads to better clinical decision-making including better risk management
3. Reduces duplication of clinical and administrative work
4. Enables coordinated and continuous care

This group were less likely to mention involving people in decision-making and giving them greater agency in their own care.

This group were also asked how they could promote the use of SECRs and the most frequent response was sharing experience of its use with others. Another strategy was to get involved in the development and improvement of SECRs.

> "I can read about a client's history before meeting them which comforts the client as they don't have to share their story over and over. This is especially important in the field of mental health. I can also see what other service providers are doing with them while I am working with the client. This allows for me to treat the client in a way that supports other work that they are doing. Finally, my notes and reports can be seen by others so that those who follow up with the client after me can support a smooth transition."
>
> **Provider**

3. Policymakers

Policymakers at national and regional levels, have a role in creating the conditions that allow SECRs to scale and spread. 66 per cent of policymakers said the providers in the system they oversaw had access to SECRs always or most of the time. 67 per cent of policymakers experienced these as being shared across organisational boundaries, a higher level than either people at the centre of care or providers.

Of those who did experience records shared across organisational boundaries, 75 per cent said this led to better experience of coordinating care and providing continuity. The reasons they gave for this were much more distributed than other groups. Among the varied reasons SECRs contribute to better integration were:

1. Better continuity and coordination
2. More accessible information
3. Reduces duplication of clinical and administrative work
4. Timely information
5. Better communication between professionals

This group were also less likely to mention involving people in decision-making and giving them greater agency in their own care than people at the centre of care.

This group were also asked how they could promote the use of SECRs and the most frequent response was to get involved in the development and improvement of SECRs. Policymakers also saw themselves in having a role in ensuring investment in SECRs, enabling co-design and creating a promoting legislative and regulatory environment.

> "Allows regional divisions to be overcome by enabling citizens to receive care throughout the entire country (and in the future, Europe) by ensuring complete information to the physician."
>
> **Policymaker**

4. Researchers

Researchers have a role in sharing the lessons learnt about SECRs implementation, what works and what does not. 57 per cent the researchers said the providers in the system they research and evaluate had access to SECRs always or most of the time. Only 30 per cent of researchers experienced these as being shared across organisational boundaries, the lowest level of any of the four groups responding to the survey.

Of those who did experience records shared across organisational boundaries, a low number to start with, 78 per cent said this led to better experience of coordinating care and providing continuity. The reasons they gave for this were similar to other groups. Among the varied reasons SECRs contribute to better integration were:

1. Better risk management of care through greater visibility of information
2. Better continuity and coordination
3. Reduces duplication of clinical and administrative work
4. More efficient care
5. Better clinical decision-making

This group were also less likely to mention involving people in decision-making and giving them greater agency in their own care than people at the centre of care.

When asked how they could promote the use of SECRs, this group's most frequent response was to get involved in the development and improvement of SECRs. Researchers also saw themselves in having a role in promoting inter-operability of information systems, training and capacity-building for all stakeholders involved in implementation and supporting the development of enabling strategies and policies.

> "Critical information from patients and caregivers is shared amongst providers. In research we have seen this improve care coordination, reduce patient and caregiver burden (not wanting to "re tell" their stories), and prevent or address medication errors. Unfortunately, this is not applied consistently. Sharing records with specialists seems to be the most problematic and least common."
>
> **Researcher**

Country-level findings

While our analysis focused on group differences, we did note that preliminary examination of country-level patterns suggested geographic variation in SECR adoption. For example, Canada showed 58 per cent sharing rates as opposed to the United Kingdom (UK) which showed 20 per cent in the two largest country samples. Cross-country differences suggest that SECR adoption is closely linked to national policy and infrastructure. Results from smaller samples such as Portugal, Ireland, Spain, and the United States of America should be seen as indicative only, but the larger Canada–UK comparison points clearly to country context as a critical driver of success.

It should be noted that, with only three countries having adequate sample sizes ($n \geq 30$), country-level analysis cannot be reliably conducted. A fuller geographic analysis would require more targeted sampling, and this could be a valuable direction for future research.

Focus group discussions

The focus group discussions allowed participants to explore some of the above themes in more detail, including the reasons for the experiences that were shared in the survey and what can be done to accelerate the use of SECRs to enable care coordination and continuity.

Terminology and importance:

There was a recognition from some participants that SECRs started as organisational administrative and billing mechanisms. Current SECRs have moved beyond this but in some cases just to become repositories of activity linked to people at the centre of care.

> "By law, everything that happens with a patient has to be put into the repository, but it is just a repository." **Provider**

When implemented to support coordination, SECRs are just a tool – they are the technical component of a social process that requires people to come together to share decision-making and planning of care collectively. In this context, SECRs are important but not sufficient to enable care coordination and continuity.

> "But I would say ... the enablers are not the medical records. It's the situation that we are actually sitting together, speaking towards different professionals, so different specialists." **Person at the centre of care**

For some participants, the lack of health and social care record integration is a significant barrier to care coordination and continuity.

> "What we all know now is that rarely do you find somebody that is just living with diabetes. They've usually got other needs, be they health or social care, which is where the integrated care aspect comes in. And so of course the electronic diabetes shared care record only captures this bit of the person. It's not holistic." **Researcher**

Experience of access and use

Where SECRs are in use, the participants identified both benefits and several remaining challenges ranging from the quality of the information in SECRs through to digital health literacy.

Benefits we see from SECRs today

Much of the discussion on benefits of SECRs was aspirational, focused on a future that is still not realised for many of the reasons stated above. This was particularly the case for the new working practices of shared decision-making and care planning. There was much agreement that including people at the centre of care in decision-making and care planning is the right thing to do but little sense it was happening in reality.

> "We are moving from paternalistic to shared medicine, but it's a long path. Many patients bring health data from apps, which should be incorporated into decisions. Polic-ymakers are starting to think about this, but it's a challenge." **Policymaker**

There were some concrete examples of developments aimed at enhancing people-centred care coordination and continuity. We heard of SECRs where the life goals of the person at the centre of care are entered, sometimes by the person themselves, and this information is used in consultations to guide treatment and care pathways. We also heard examples where the use of shared care records by health and care providers was reducing duplication and waste and enhancing safety by helping different professionals communicate better.

> "So one of the authentic resources we are now developing is the patient's life goals. That will be the only authentic source that is only accessible for patients and the informal care providers that support them. And that patient would write what his or her life goals are, what makes their lives worthwhile to be lived and this has in the future to have a central position when you discuss about what the best choices are in the care trajectory of a certain patient with certain conditions." **Provider**

> "I got a small thrombosis at some point and so there was a need for a blood thinner, but for a blood thinner it was important to know that I also had a blood cancer and I was on that other drug. And that was there available in that regional network." **Person at the centre of care**

Beyond the level of individual care, at population level, examples were shared where population level data extracted from SECRs are being used to make service improvements aimed at people's experience of care some of which is directed at better care coordination.

> "I do drive continuous improvement and care redesign using extracted, transformed, and downloaded data. So we do not directly go into electronic medical record on a daily basis to do that, but there is a small amount of that kind of improvement and policymaking work and real-time decision-making work done within the EMR (electronic medical record) system itself. People do access the EMR for that kind of improvement decision-making or real-time decision-making." **Policymaker**

Challenges in meaningful use of SECRs

SECRs contain a lot of data which is not used or usable and data is duplicated on multiple systems. Sometimes data is "hidden" particularly if held on pen and paper systems. Both of these have obvious consequences for coordination and continuity of care by reinforcing fragmentation.

> "We put a lot of data into it, but it's so time consuming to find where it is. It's got so much data." **Person at the centre of care**

> "Some departments are pen and paper still. So even the departments and the services that are digitalized have some processes that [use] pen and paper. For example, in obstetrics, when someone is born, the nurse introduces data in the computer, but then they need to print a paper that they will take to the administrative person to actually put the baby into a digitalized system. So it's something that occurs because the system doesn't communicate with the other system." **Researcher**

In people's experience, not all health and care professionals are given equal access to the data and information in SECRs.

> "If I may say something, I think, first of all, I have to say that in Slovenia, all the practitioners have access to the patient's records by definition, but this includes mostly doctors. For nurses, it's a different thing. Nurses are not allowed to see everything." **Policymaker**

Poor digital and data literacy amongst people at the centre of care are seen as real impediments to the use of SECRs for sharing information and decision-making.

> "Never forget that up to 40 per cent of your patients, and that's not only in my country, will have problems with digital literacy so that you don't put all your activities and your focus only in that approach." **Provider**

As a counterpoint, it was pointed out that without people at the centre of care and health and care providers being included in the development and use of SECRs people cannot be expected to become more digitally and data literate.

> "The patient is the fundamental element of the chain that is about that integration and if that citizen does not have the tools at hand that would allow that individual before, during and after any kind of interaction with a care system, then you cannot expect in any shape and form an approach that leads to more health literate citizens to happen" **Researcher**

Limitations and problems with SECRs

The discussion largely revolved around the barriers to development and implementation of SECRs rather than their embedded use and integration into everyday workflow, which unsurprising given the limited deployment. The issues raised echo what is known in the peer reviewed and grey literature on the barriers to technology implementation in health and care (1): information governance coopted to stop data sharing, lack of technical infrastructure, poor quality data, poor internet connectivity, poor system interoperability, and lack of investment in technology for future-proofing. However, we also heard examples of how SECRs are having some unintended consequences. Participants shared examples where health and care professionals are limiting or modifying what is put in SECRs.

> "We can see in Sweden that should the record be open the electronic records for patients and informal care has made a clinicians write less data in the system." **Person at the centre of care**

Providers in our sample were more likely than other groups to express concern about what giving people at the centre of care more control over their data could mean from a clinical risk perspective.

> "And the only negative I can think of is how much control does the patient have and could they potentially choose not to share something with somebody and therefore could it lead to this problems." **Provider**

As a counter point, other providers who have direct experience of more input and control by people at the centre of care and sharing records across organisations, have seen positive benefits of this greater integration.

> "For instance, we've had a big debate about whether or not to tick the box to allow patients who've got their own portal to see the actual written clinical notes from a general practice consultation. And to start with, like 10 years ago, it was like a hard no. Then the odd practitioner said, 'Oh, well, actually, we just tick the box.' And, you know, to be honest, some of the people, they could see everything and revise it and review it and everything. It was much simpler. And then they start to use it and then before you know it you're absolutely dependent on it because you can see from the shared record like what's been happening in the hospital and where the person is on the waiting list and what the triage thought and what the radiology was when they went to somewhere miles away and it's not in your inbox but it's in that shared record. So I think just making it so that it's indispensable." **Provider**

Several participants shared experience of how this shared information was driving changed professional practice, leading to better care coordination.

> "For the first time in the click, they can see that the same person is having like 10 primary care consultations. And is visiting like different specialists and so they realise that we have to work together and we have to connect." **Provider**

People shared examples of SECRs that were designed for single conditions and very effective within a single clinical pathway but described how they have contributed to fragmentation of care because they are not person-centred nor do they enable data sharing.

> "It was amazing that we are building up the care coordination system due to one diagnosis, not to several diagnosis. It was so sure that the ones that were reading neural quality, they were just looking for the spots that was focusing on the tumour and the ones that were reading the spots on the future on the pregnancy, the women health was not reading it in each other."

People linked fragmented information to the question of control and ownership of data and information. There was some discussion about how this is and should be changing as we move towards more people-centred care with people at the centre of care having more access to and control over their own health and care data. The fragmentation of provision, including provider ownership and governance exacerbates this further with hospital and primary care for example, rarely sharing a single SECR.

> "There are plans to establish an electronic health record to integrate all data. This will be a challenge, as primary care is based in community health centres and hospitals are state-owned." **Policymaker**

There is sense that digitisation of data in and of itself is insufficient without thinking about how this data is joined up from the outset. We heard experiences of multiple digital systems contributing to more and greater fragmentation.

> "Even though it was all digital, they were digitally lost. So the assumption that we as an advanced sort of society like the Danish one, well, we can just get lost in other ways. So data can still be very fragmented." **Researcher**

Accelerating progress on SECRs

Participants were agreed that progress needed to be sped up to deliver on the benefits but quality should not be compromised. To ensure that this balance is achieved, some solutions were proposed and some examples of these in practice shared.

Providers, researcher and policymakers highlighted training and capacity building for digital literacy as an essential investment. One participant shared how this was built into the implementation of an electronic healthcare record in his state.

> "So in my experience in..., at least, you know, we have for the last seven years been investing into the transition from traditional systems into EPIC. But lo and behold, it's not just the investment to buy the EPIC system and use it, you know, the EPIC usage investment into informaticians, data scientists and clinicians who are trained to build their own reports, configure their own reports. And that increases my manpower costs as well, not just my IT costs." **Policymaker**

Involving end-users, health and care professionals usually, in the design and development of SECRs has been lacking in many of the systems currently in place. This is not always the fault of developers but sometimes developers are not allowed to take up clinical time with user-centred design by senior clinical leaders.

> "Professionals and providers have an important role to play there because if you leave this to IT people and engineers you will end up with something that looks very nice but will not be useful for our daily practice. So we have no other choice than to participate and to co-create in the process of making this happen." **Provider**

Leaders in health and care systems have a role to play in creating the conditions for SECRs to scale by setting standards and expectations for information sharing, investing in capacity building and providing feedback on how the use of SECRs is benefiting people at the centre of care, providers and the wider health and care system.

Taking a step back: applying theory to the practice shared

One theme that emerged from the focus groups was the limitation of SECRs as a technical solution to a complex social process of care coordination and continuity. To explain our findings, we used the theoretical lens of normalisation process theory (NPT).[10,11]

In the words of its original authors, May et al, NPT provides a way to understand and explain social processes through which new ways of working are incorporated into the "way things are done" in healthcare and other settings, essentially, how new ways of working get "normalised".

The theory is concerned with three core problems:

1. How new practices are implemented
2. How they are embedded and become routine, or not
3. How they are integrated, so reproduced and sustained in an organization or institution

It is particularly well suited to looking at the implementation of complex changes like shared electronic care records because it allows us to examine how knowledge is held, transferred, and created within and across different groups and the work that various actors (people at the centre of care, health and care providers, service managers, and policymakers) have to do to put that new knowledge into practice.[12] This is important because we know a lot about what people think should happen to share information for care coordination and continuity but less about what they experience and do.

NPT has been used in analysing the implementation of electronic health records[13,14] and other digital tools in healthcare[15–17] and illuminates the social process of technology implementation in a way that allows us to understand what is going on under the surface.

There are four core mechanisms of NPT; coherence, cognitive participation, collective action and reflexive monitoring.[18] These are explained in the figure below.

The mechanisms of normalisation process theory in SECRs

Coherence

When faced with a problem and the suggested solution, this is the work people do to make sense of both together

Cognitive particpation

The relational work that people do to think about the new working practices that need to be developed

Collective action

The work that people do together to turn the thinking about new working practices into action

Reflexive monitoring

The work people do to learn as they work in the new ways and reflect what needs to adapt in response to learning

These core mechanisms happen in context and this context both shapes and is shaped by the core mechanisms.[19]

In applying this framework to the descriptive analysis of the focus group discussions, we see patterns emerging from the data that may help inform how we plan and implement SECRs in the future. The findings are summarised in the table below.

Core mechanism	Descriptive theme
Coherence (participants' understanding of why SECRs are implemented)	• SECRs are important but not sufficient for coordination • SECRs can enable providers to work together for better coordination • SECRs can bring people at the centre of care into the decision-making and planning process
Cognitive participation (willingness to engage with and invest time into the SECRs)	• Enhance the digital literacy of users through co-design, co-implementation and ongoing feedback • Training and capacity building as part of implementation and embedding
Collective action (the extent the SECRs are used)	• Experience of SECRs in practice – mainly as information repositories • Impact on practice for single conditions management • Change to current practice including the effect on working relations between providers and people at the centre of care
Reflexive monitoring (appraising the implementation of SECRs)	• Barriers – perception and reality • Experience is limited to electronic health records (EHRs) mainly and inclusion of social care is rare • Importance of linking back to coherence – the purpose for SECRs • How learning happens and contributes to embedding and integrating SECRs

The coherence of SECR implementation

People at the centre of care and researchers were the two groups to highlight that SECRs are just a tool. The process of care coordination is a social one that requires providers to work together and with people at the centre of care collaboratively. SECRs can make this process much easier but alone it is not enough. You can have ECRs that act to collect and hold information but these don't in and of themselves create the conditions for care coordination and continuity. ECRs are more often not shared, the data that is entered into them is not joined up and often relates to one condition or care pathway sometimes within a single institution. This further exacerbates fragmentation rather than enabling coordination.

Providers shared examples where the use of shared care records by health and care providers was reducing duplication and waste especially at points of transition in care such as hospital discharge or even when being transferred from one part of a hospital to another (for example, post-surgery to a general medical ward). We also heard examples from people at the centre of care where shared access to care records enhanced safety by avoiding medication errors that arose from care fragmented across specialties and providers.

Much of the discussion on benefits of SECRs was aspirational, focused on a future that is still not realised. This was particularly the case for the new working practices of shared decision-making and care planning. There were examples shared of SECRs where the life goals of the person at the centre of care are entered and this information is used in consultations to guide treatment and care pathways.

Cognitive participation

Providers particularly highlighted poor digital and data literacy amongst people at the centre of care as real impediments to the use of SECRs for sharing information and decision-making. The paradox that was pointed out by some is that if people at the centre of care and health and care providers continue to be excluded from the development of SECRs and feedback on their ongoing implementation and embedding, people cannot be expected to become more digitally and data literate. While much is made of co-design and user-centred design with developing SECRs, the involvement of end-users, health and care professionals usually, in the design and development of SECRs has been lacking in many of the systems currently in place. This is not always the fault of developers but sometimes developers are not allowed to take up clinical time with user-centred design by senior clinical leaders.

Training and capacity building for digital literacy is therefore an essential investment in terms of expenditure but more importantly time. Policymakers and organisational leaders play a particularly important role in ensure that this investment is protected particularly after the initial 'go-live' of a SECR.

Collective action

Providers recognition that many 'off-the-shelf' SECRs started as primarily billing or claims systems in health systems financed through insurance. There is an acknowledgement that they systems have moved beyond this but this initial purpose is still apparent in a lack of flexibility. SECRs can be viewed by providers and people at the centre of care as mere repositories of activity linked to people at the centre of care. However, several providers did share experiences of how shared information in an SECR was driving changed professional practice leading to better care coordination by prompting professionals to connect on a persons care to manage and avoid duplication.

There were examples of SECRs in use in several countries that have been designed for single conditions and very effective within a single clinical pathway. However, as useful as these are to those providers working on this single condition or pathway, such records have contributed to fragmentation of care for the person at the centre of care particularly those people who need coordination most, people living with multiple chronic conditions.

The issue of giving access and control of data to people at the centre of care is a point of debate for providers with some expressing concern about the potential clinical risks of doing so, for example, if a person deliberately withheld important information. As a counter point, other providers who have direct experience of more input and control by people at the centre of care, have seen positive benefits of this greater involvement. People at the centre of care related experiences of the effect of information not being shared by providers, where they themselves were responsible for filling information gaps and thus managing the clinical risk.

Reflexive monitoring

There are many perceived barriers to the implementation, embedding and integration of SECRs. In reality, most of these are that the stage of implementation.

People still see the lack of health and social care record integration is a significant barrier to care coordination and continuity particularly for older people. Almost all of the experience from focus group participants is of electronic health records (EHRs), with some shared across secondary, community and primary care.

Even within single provider organisations, data is, poor quality, unusable, fragmented and duplicated on multiple systems. It is also sometimes "hidden" from digital access if held on pen and paper systems, a common occurrence in health systems still. Both of these have obvious consequences for coordination and continuity of care by reinforcing fragmentation but there is a sense that this is not being captured systematically as part of the any process of monitoring and evaluation of implementation of SECRs.

The issue of unusable or poor-quality data being input into SECRs goes back to the core mechanism of coherence. When people are unclear about the use case for a SECR and see no value in their own work, they are less likely to pay attention to the quality of the data they are inputting. An example of capacity-building that explicitly focused on this and the positive effect of this on data quality, was shared by a participant.

None of the participants in the sample shared examples of monitoring and evaluation of the implementation of SECRs leading us to pose the question – how will we know if the systems are contributing to care coordination and continuity?

Limitations

The respondents to the survey and participants in focus groups were self selecting and all had a particular interest in SECRs so they are not representative of the wider population of people at the centre of care, providers, policymakers and researchers. However, their deep knowledge of SECRs in practice enabled us to move beyond the aspirational to reflect on what is happening for in the real-world of SECRs.

Additional methodological limitations were identified during data analysis:

Sample Composition

Uneven group sizes:
Policymakers are underrepresented (n=18 vs. n=58 for providers) which limits policy conclusions

Country-level patterns/bias:
Nearly half of the responses (46%) came from Canada and the UK limiting global insight.

Data considerations

Potential clustering effects:
Multiple responses may be related due to shared organisational / geographical contexts, affecting statistical assumptions.

Methodological constraints

Stakeholder categories/ definitions:
Broad groupings of stakeholders may mask within-group differences (e.g., types of healthcare providers).

Timing:
The single data collection period may not capture seasonal or policy-change variations.

Conclusions

Comparing the findings of this survey across countries, having a national or regional policy and infrastructure for shared care records is probably the most important enabling factor of SECRs adoption and use.

A gap between the experience of people at the centre of care and health and care providers in having access to and using SECRs is evident in this survey. One implication of this is that SECRs continue to be developed as a service optimization solution not one to enable and empower people receiving care.

Shared electronic care records are an important tool in coordinating continuous care. While electronic care records are increasingly in use in high income countries, the records are still not consistently shared across organisations and sectors, for example health and social care.

Where SECRs are in use and shared there are benefits seen in care coordination but SECRs alone are not enough to enable integration. Human relationships between health and care providers and people at the centre of care are pivotal.

The results of this survey support published research on the implementation of SECRs which show that SECRs are still at the normalising stage of implementation. Experiences of embedding SECRs in everyday workflow are few and examples of integration into the everyday are rare. We have a long way to go to achieve the promise of basic shared electronic care records as a integrated information tool to promote care coordination and continuity.

Our findings underscore the assertion that to accelerate SECR adoption, it will be essential for all stakeholders to acknowledge that normalising the use of SECRs is a social and technical activity not just a technical one. Mobilising inter-disciplinary teams, that include people who are at the centre of care, in the design, implementation and evaluation of SECRs is the best possible starting point.

References

1. Cresswell K, Anderson S, Mozaffar H, Elizondo A, Geiger M, Williams R. Socio-organizational dimensions: the key to advancing the shared care record agenda in health and social care. J Med Internet Res. 2023;25:e38310.
2. White PJ, Casey BP, Cleary O, Finn E, O'Connor K, Coen N. Co-design with Integrated Care Teams: Establishing Information Needs. Int J Integr Care. 2023;
3. Dong C, Liu J, Mi J. Information-driven integrated healthcare: An analysis of the cooperation strategy of county medical community based on multi-subject simulation. In MDPI; 2023. p. 2019.
4. Steele-Gray C, Gagon D, Guldemond N, Kenealy T. Digital Health Systems in Integrated. In: Handbook Integrated Care. Springer Nature; 2021. p. 479.
5. Tapuria A, Porat T, Kalra D, Dsouza G, Xiaohui S, Curcin V. Impact of patient access to their electronic health record: systematic review. Inform Health Soc Care. 2021;46(2):194–206.
6. Kooij L, Groen WG, van Harten WH. The Effectiveness of Information Technology-Supported Shared Care for Patients With Chronic Disease: A Systematic Review. J Med Internet Res. 2017 June 22;19(6):e221.
7. Perera G, Holbrook A, Thabane L, Foster G, Willison DJ. Views on health information sharing and privacy from primary care practices using electronic medical records. Int J Med Inf. 2011;80(2):94–101.
8. Chute C, French T, Raman S, Bradley J. User requirements for comanaged digital health and care. J Med Internet Res. 2022;24(6):e35337.
9. Chester H, Hughes J, Bowns I, Abendstern M, Davies S, Challis D. Electronic information sharing between nursing and adult social care practitioners in separate locations: a mixed-methods case study. J Long-Term Care. 2021;(2021).
10. May CR, Mair F, Finch T, MacFarlane A, Dowrick C, Treweek S, et al. Development of a theory of implementation and integration: Normalization Process Theory. Implement Sci. 2009;4(1):29.
11. Murray E, Treweek S, Pope C, MacFarlane A, Ballini L, Dowrick C, et al. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. BMC Med. 2010;8(1):63.
12. McEvoy R, Ballini L, Maltoni S, O'Donnell CA, Mair FS, MacFarlane A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. Implement Sci. 2014;9(1):2.
13. McCrorie C, Benn J, Johnson OA, Scantlebury A. Staff expectations for the implementation of an electronic health record system: a qualitative study using normalisation process theory. BMC Med Inform Decis Mak. 2019;19(1):222.
14. Scantlebury A, Sheard L, Watt I, Cairns P, Wright J, Adamson J. Exploring the implementation of an electronic record into a maternity unit: a qualitative study using Normalisation Process Theory. BMC Med Inform Decis Mak. 2017;17(1):4.
15. Mishuris RG, Palmisano J, McCullagh L, Hess R, Feldstein DA, Smith PD, et al. Using normalisation process theory to understand workflow implications of decision support implementation across diverse primary care settings. BMJ Health Care Inform. 2019;26(1):e100088.

16. Glynn LG, Glynn F, Casey M, Wilkinson LG, Hayes PS, Heaney D, et al. Implementation of the SMART MOVE intervention in primary care: a qualitative study using normalisation process theory. BMC Fam Pract. 2018;19(1):48.

17. McCarthy S, Fitzgerald C, Sahm L, Bradley C, Walsh EK. Patient-held health IT adoption across the primary-secondary care interface: a Normalisation Process Theory perspective. Health Syst. 2022;11(1):17–29.

18. May C, Rapley T, Mair F, Treweek S, Murray E, Ballini L, et al. NPT. Normalization Process Theory On-line Users Manual, Toolkit and NoMAD instrument [Web page]. 2015;

19. May CR, Johnson M, Finch T. Implementation, context and complexity. Implement Sci. 2016;11(1):141.

Appendix 1: Focus group design

Objectives

In more depth and based on responses to the Annual Survey:

- Explore the lived experiences of SECRs in different user groups.
- Understand how SECRs enable or constrain coordination and continuity of care.
- Understand the solutions for promoting SECRs from the point of view of health and care providers, policymakers and funders, and researchers.

Recruitment

Focus group participants were drawn from survey respondents who volunteered to participate when responding to the Annual Survey 2025 and provided contact details. They came from 17 countries. IFIC also identified participants in our global network and invited them to participate in the focus groups. In total, we invited 40 people to take part in the focus groups. We held seven focus groups over July 2025. Each focus group was made up of participants from one of the following groups:

1. People at the centre of care (PACC) who use care and informal carers
2. Health and care workers and service managers
3. Policymakers and funders
4. Researchers and academics

Focus group category	People at the centre of care (PACC)	Policymakers	Providers	Researchers	Total
No. of groups	1	1	3	2	7
No. of Participants	3	3	7	9	22

Focus Group Format

Each group had a maximum of 5 participants to allow for in-depth discussion while ensuring manageability in an online format. Sessions lasted for 60 minutes and were conducted via Zoom or Teams. The IFIC researcher started each focus group with the following:

> "This year, the Annual Survey focuses on shared electronic care records (SECRs) and their role in helping or hindering care coordination and continuity. In the survey, we asked people from across the system to share their experience with or without SECRs. Today, we want to go deeper into how SECRs are working—or not—and what still needs to happen."

They then presented some high-level quantitative findings from the Annual Survey to stimulate discussion.

Consent and Data Protection

Participants were asked to consent to take part prior to the focus group. All focus group participants were asked to re-confirm verbal consent at the start of the focus group. Sessions were recorded with explicit permission for analysis purposes only. Focus groups were facilitated by a trained IFIC researcher.

Discussion Framework

- The discussion structure covered the following topics for all groups:
- Experience of access and use of SECRs
- Impact of SECRs on coordination and continuity
- The reasons for different experiences across groups based on the quantitative findings of the Annual Survey presented to the focus group participants
- Solutions to promote SECRs in different countries and settings

About the International Foundation for Integrated Care (IFIC)

The International Foundation for Integrated Care (IFIC) is a not-for-profit foundation dedicated to improving the lives of people and communities by advancing the science, knowledge, and adoption of integrated care around the world.

IFIC's vision is that individuals, families, and communities benefit from person-centred, coordinated care and support that enables them to live healthy and fulfilling lives. IFIC works to overcome the fragmentation in health and care systems by promoting models of care that are holistic, co-produced, continuous, coordinated, equitable, and sustainable.

As the leading international voice for integrated care, IFIC brings together researchers, health and care professionals, policymakers and people, families and communities. IFIC provides a unique platform for collaboration, knowledge exchange, and innovation to drive system change.

IFIC delivers impact through:

- **The International Journal of Integrated Care (IJIC)** – our open-access, peer-reviewed publication sharing global evidence and best practice
- **International conferences and regional networks** – connecting people and ideas across sectors and borders
- **The Integrated Care Academy** – offering education and training to develop the workforce needed for transformation
- **Applied research and implementation support** – bridging policy and practice to build more effective and sustainable care systems
- **Knowledge platforms and solutions** – enabling shared learning and practical action across our global community

IFIC is recognised for its excellence, transparency, collaborative partnerships, and commitment to open access and continuous quality improvement.

United Kingdom
Annexe Offices
Linton Rd
Oxford OX2 6UD
United Kingdom

The Netherlands
The Base B
Evert van de Beekstraat 1-104
Schiphol Airport 1118CL
The Netherlands

Email: info@integratedcarefoundation.org
Linkedin: mylinkd.in/IFICInfo
Facebook: facebook.com/IFICinfo
Vimeo: vimeo.com/integratedcare
Bluesky: @IFICinfo

IFIC International Foundation for Integrated Care

IFIC ANNUAL SURVEY 2025

Connecting Care Information

Are shared electronic records the key to overcoming fragmentation?

IFIC International Foundation for Integrated Care