IFIC ANNUAL SURVEY 2023

Are we there yet?

People's views on how far we have advanced in providing continuous and coordinated care

Authors
Dr Arturo Alvarez-Rosete
Dr Edelweiss Aldasoro
Alejandro Gil-Salmerón
Dr Pilar Gangas
Dr Niamh Lennox-Chhugani

IFIC International Foundation for Integrated Care

Key messages

The 2023 IFIC Survey got views across three different stakeholder groups on how they **see continuity and coordination of care happening** in their own settings.

Service users	Health and Care providers	Policymakers

- Service users, care providers and policymakers have responded that continuity and coordination of care are already happening. **People see small and moderate advances**, "signs of a new culture of integration" visible through experiments and local initiatives.
- But we are not there yet: effective continuity and coordination of care is **not yet fully established**.
- In general, people have **more positive views about achievements with care continuity over time than with coordination of care** across multiple providers and settings.

Service users have a more negative perception than providers of the degree to which care services are done with continuity and in a coordinated manner. Several service users noted that **continuity and coordination ultimately fall on them:**
"I am the person who co-ordinates my care".

Health and care providers see improvements happening at the organisational level rather than at the system level.

There is a sense of optimism from **policymakers and researchers** regarding advances in care continuity and coordination over the past years, although improvements are not consistent across the sectors or in countries, hence still much progress has to be made.

- **The tools and interventions that can effectively promote continuity and coordination are known**. While none of these is perceived as having gone very far, "Continuity with the same professional" and "Regular interdisciplinary team meetings" stand slightly above the rest. Advancements on the "Continuity with the same professional" mechanism are mostly noted by service users.
- Promising news is that this **slow-progress perception is widespread**, from Nigeria to Canada to Singapore.
- However, "**changes are still embryonic**", local and not consistent within and across countries. **Hence, we are not there yet! There is still much progress to be made!**

Contents

Introduction

The International Foundation for Integrated Care (IFIC) conducted its second annual survey on integrated care, with a specific emphasis on **collecting the experiences** of our network regarding **how coordinated and continuous care is today** in different contexts, countries and from various stakeholder viewpoints.

This report provides a concise overview of the survey findings.

Background

In 2022, IFIC ran the first annual survey on integrated care by asking to our network: **What features of integrated care matter to the policymakers, practitioners, researchers, patients and caregivers with experience of integrated care in different countries/systems today?** The survey aimed to capture respondents' unprompted understanding of integrated care and what it meant to them.

Respondents demonstrated **a range of understandings across three key elements:**

The 'who'

extending from descriptions that centre on the 'patient' to those that encompass 'communities'.

The 'what'

pertaining to what integrated care accomplishes differently compared to non-integrated care, extending from the coordination of services to addressing the concerns of individuals and communities.

The 'how'

which addresses the distinctive way integrated care is delivered compared to traditional service delivery models.

Many respondents articulated integrated care in terms of expanding the structural capacity and resources within health and care systems, including physical resources (e.g. setting up new health and care beds), human resources (e.g. introducing new professional roles such as case managers) and/or knowledge resources (e.g. introducing clinical guidelines and agreed protocols, etc.). However, several responses emphasized that integrated care models involve a shift in values and organizational culture.

This year 2023 our goal has been to **explore further people's views on the practice of integrated care.**

Our specific focus has been on assessing the extent of progress made delivering **continuous and coordinated care**. While these features of integrated care – continuity and coordination- are very often used interchangeably, they refer to different but closely interconnected dimensions: continuity pertains to the temporal aspect, involving care across time, while coordination is associated to the spatial dimension, encompassing care across providers, professionals and geographies).

Hence, the 2023 IFIC Survey has sought to gather the views of the members of our network on how they see continuity and coordination of care happening.

IFIC seeks to gain a better understanding of:

What mechanisms, approaches and interventions make continuity and coordination of care possible?

Which mechanisms are considered most valuable (really effective) to promote care coordination and continuity?

Continuity and coordination of care: conceptual and analytical approach

Continuity and coordination as essential elements of the integrated care definition:

"The central defining features of integrated care which cuts across all stakeholders (people and communities, individual providers, a system of organisations, and policymakers) are continuity and coordination. Continuity occurs temporally and coordination occurs spatially. For the person at the centre of care, their experience is seamless across formal/informal care, professional, organisational and sectoral boundaries and continuous over time. For providers, they design care to effectively manage transitions from one profession, organisation or sector to another over multiple episodes of care. For policymakers, integrated care requires them to ensure that the wider context supports continuity and coordination and does not work against them"[1]

[1] Lennox-Chhugani N. Integrated Care – Defining for the Future through the Eye of the Beholder. International Journal of Integrated Care [serial online] 2021;21(3):13. [cited 2023 30 August]. Available from: https://doi.org/10.5334/ijic.6427

In line with the literature, the survey has understood **continuity of care as a temporal dimension**:

"Continuity of care and services that are provided across the life course"[2]

"The degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time and consistent with their health needs and preferences"[3]

"Continuity is defined as the patient's experience of a consistent approach to care, often as a result of a continuing relationship with the same healthcare professional"[4]

"Continuity is the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context. Continuity of care is distinguished from other attributes of care by two core elements–care over time and the focus on individual patients"[5]

Continuity of care in primary care has been shown to have demonstrable effects on patient mortality and the quality of care as experienced by patients[6,7]

On the other hand, the survey has understood **coordination of care as occurring spatially:**

The literature sees coordination happening "across different providers and settings"[8,9]

Co-ordinate is, together, to order the care which different providers give to a patient, so that the results are greater than the sum of each provider's care. Clinical care coordination is where two or more providers – individuals or organisations – communicate or collaborate with each other and the patient to provide care that takes account of other's actions"[10]

Coordination of care is a central tenet of integrated care and studies have shown that care coordination has a positive impact on health outcomes and patient experience [11,12]

[2] Ferrer L, Goodwin N. What are the principles that underpin integrated care?. International Journal of Integrated Care [serial online] 2014;14(4):null. [cited 2023 30 August]. Available from: https://doi.org/10.5334/ijic.1884

[3] World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018 [cited 2023 30 August]. Available from: https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y

[4] Øvretveit J. Does clinical coordination improve quality and save money? A summary of a review of the evidence. London: Health Foundation; 2011 [cited 2023 30 Aug]. Available from: https://www.health.org.uk/sites/default/files/DoesClinicalCoordinationImproveQualityAndSaveMoneyVol2_fullversion.pdf

[5] Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R et al. Continuity of care: a multidisciplinary review. BMJ [serial online] 2003; 327 :1219. [cited 2023 Aug 30]. Available from: doi:10.1136/bmj.327.7425.1219

[6] Baker R, Freeman GK, Haggerty JL, Bankart MJ, Nockels KH. Primary medical care continuity and patient mortality: a systematic review. British Journal of General Practice [serial online] 2020 Aug 27;70(698):e600-e611. [cited 2023 Aug 30]. Available from: doi:10.3399/bjgp20X712289

[7] Chan KS, Wan EYF, Chin WY et al. Effects of continuity of care on health outcomes among patients with diabetes mellitus and/or hypertension: a systematic review. BMC Family Practice [serial online] 2021; 22:145. [cited 2023 Aug 30]. Available from: https://doi.org/10.1186/s12875-021-01493-x

[8] Ferrer L, Goodwin N. What are the principles that underpin integrated care?. International Journal of Integrated Care [serial online] 2014;14(4):null. Available from: https://doi.org/10.5334/ijic.1884

[9] World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018 [cited 2023 30 August]. Available from: https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y

[10] Øvretveit J. Does clinical coordination improve quality and save money? A summary of a review of the evidence. London: Health Foundation; 2011 [cited 2023 30 Aug]. Available from: https://www.health.org.uk/sites/default/files/DoesClinicalCoordinationImproveQualityAndSaveMoneyVol2_fullversion.pdf

[11] Powell Davies G, Harris M, Perkins D, Roland M, Williams A, Larsen K, McDonald J. Coordination of care within primary health care and with other sectors: A systematic review. Sydney: Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, University of South Wales; 2006. [cited 2023 30 Aug]. Available from: https://nceph.anu.edu.au/files/final_25_powell_davies_pdf_17464.pdf

[12] Karimi M, van der Zwaan L, Islam K, van Genabeek J, Mölken MR. Evaluating Complex Health and Social Care Program Using Multi-Criteria Decision Analysis: A Case Study of "Better Together in Amsterdam North". Value Health [serial online]. 2021 Jul;24(7):966-975. [cited 2023 30 Aug]. Available from: doi: 10.1016/j.jval.2021.02.007.

A WHO report has explored the range of strategies and interventions that facilitate both care continuity and care coordination .Thus, on the one hand, the report listed a range of approaches and interventions for achieving continuity of care, organised along four dimensions – interpersonal, longitudinal, management and informational continuity (Table 1). On the other hand, it collected the range of approaches and interventions for achieving coordination, organised along three dimensions – sequential coordination, parallel coordination and system enablers (see Table 2). Together, this comprehensive listing has proved useful to frame the questions of the survey.

Table 1. Range of approaches and interventions for achieving continuity of care

Dimensions	Approaches / Interventions
Interpersonal continuity	• Continued relationship and trust among providers, patients and caregivers • Care by the same central providers for all care needs • Flexible, consistent, adaptable care along the continuum • Care adapted to patients' behavioural, personal, cultural beliefs and family influences
Longitudinal continuity	• Discharge planning from admission • Care and follow-up by a professional or team in all settings or care levels • Care navigator or community connector • Support by informal carer or social network
Management continuity	• Case management across sectors • Shared collaborative care by an interdisciplinary team • Case-finding and detection of high-risk individuals • Proactive, regular monitoring of long-term conditions • Care planning with the perspectives and recommendations of multiple providers
Informational continuity	• Positive patient-provider communication; patients informed of what and why their care is changing • Information shared among providers and settings to ensure "collective memory" • Shared, synchronized care records • Standardised, common clinical protocols in all care settings

Source: World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018 [cited 2023 30 August]. Available from: https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y

[13] World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018 [cited 2021 30 August]. Available from: https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y

Table 2. Range of approaches and interventions for optimizing care coordination

Dimensions	Approaches / Interventions
Sequential coordination	• Cross-sectoral care plans and discharge planning • Technology systems to promote information transfer and sharing of care among settings • Collocating multidisciplinary professionals • Shared, collaborative single points of entry to care • Primary and specialist care referral pathways and processes • Specialist outreach and case-finding
Parallel coordination	• Interdisciplinary teams • Care coordination roles (e.g. case and care managers, system navigators) • Formal assessment tools (e.g. goal-setting, geriatric assessments) • Individualized and tailored care plans • Self-management support • Specialist support and training
System enablers for coordination	• Role clarification and agreements withing and between sectors (e.g. accountability agreements; care pathways and protocols) • Collaborative training and education of providers to improve skills and competences • Qualitive improvement tools to assess and improve coordination • Technology enablers for care coordination

Source: World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018 [cited 2023 30 August]. Available from: https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y

Specifically, the report singled out **8 key actionable priorities**:

1

Continuity with a primary care professional

People who have continuous contact with their usual primary care provider have fewer attendances and admissions to an emergency department for conditions requiring ambulatory care and are more satisfied with their care.

2

Collaborative planning of care and shared decision-making

Having person-centred, goal-oriented planning of care and coaching that enables individuals, families and informal caregivers to be fully involved in assessment and decisions about care is a factor in successful care coordination.

3

Case management for people with complex needs

Having a proactive, continuous relationship in case-finding, assessment, care planning and care coordination to integrate the services needed by an individual reduces the probability that they will experience gaps in care.

4
Collocated services or a single point of access

Collocation of different professionals, providers and services and links with people who know local community and voluntary resources helps people who require chronic care to navigate and access the services and community support they need.

5
Transitional or intermediate care

Effective management of the transition of care from hospital to home improves the quality of care, speeds functional recovery, reduces the rate of rehospitalization and reduces the cost of care.

6
Comprehensive care along the entire pathway

Effective care coordination anticipates crises and can provide urgent responses in the evening and at the weekend by professionals who communicate well and share information from health and care records along the entire pathway.

7
Technology to support continuity and care coordination

Tools and platforms for the exchange of information facilitate adoption of practice interventions and identification of people who have multiple chronic conditions, complex circumstances or have the most to gain from care coordination.

8
Building workforce capability

Developing the skills, strengths and confidence of the wider workforce ensures that they have the competence to fill their potential roles in delivering continuity and care coordination.

In addition, the literature has suggested other key mechanisms as instrumental in levering care coordination and care continuity: the regular interdisciplinary team working; the partnering with patients and informal carers.[14]

As it will be explained in the next sections in detail, these mechanisms and interventions described by the literature will form the conceptual and analytical frameworks of this survey.

[14] Lennox-Chhugani N. Inter-Disciplinary Work in the Context of Integrated Care - a Theoretical and Methodological Framework. International Journal of Integrated Care [serial online]. 2023 Jun 19;23(2):29. [cited on 2023 Aug 30]. Available from: doi: 10.5334/ijic.7544.

Methods

Study design

A cross-sectional study design to explore the perspectives of our network members regarding the realization of care continuity and coordination. Furthermore, the study endeavours to understand the mechanisms, approaches, and interventions that contribute to the attainment of these features of integrated care.

Data collection method

An online survey was distributed globally facilitating the collection of responses from the members of our network. Survey data provides structured, often quantitative data on people's attitudes, opinions and experiences. It is possible to repeat surveys to map changes over time. This means that surveys can provide qualitative and quantitative data to understand the people, organisations and areas affected at one or a number of points in time.

The distributed online survey collected basic demographic information on respondents, including country where the respondent is based, age and gender. A segmented approach to survey questionnaire development was adopted by the research team. Respondents were then asked to ascribe themselves into the one of the following three stakeholder groups:

Users of health and care services
Patients and care givers

Practitioners
Health and care professionals and managers

Policymakers and academics
Researchers or teachers working at universities or think tanks

We designed the survey so that some questions (Q6-Q7; Q8) were asked only to one specific stakeholder group, focusing on areas that are a specific interest to those groups. The segmented survey questions are included in Appendix 1.

Hence, **both users and practitioners were asked two questions:**

To what extent they would agree or disagree that the care they receive or provide is continuous (looking at the delivery of integrated care over time) (Q6)?

To what extent they would agree or disagree that the care they receive or provide is coordinated (understood as the coordinated delivery of integrated care across multiple providers and settings) (Q7)?

Differently to users and practitioners, **policymakers and academics** were asked the question (Q8): how far the care service or system that they research or have policy making responsibility over, have advanced in the provision of continuous and coordinated care in the last 5 years.

Following, all respondents were prompted to expand on their answers in an unstructured, open-text format (Q9).

All respondents were then asked **about the approaches and interventions that support care coordination and continuity** (Q10-Q11). As mentioned above, the 2018 WHO report Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services has pointed to 8 actionable mechanisms that facilitate both care continuity and care coordination[15] Adapting this WHO list of key actionable mechanism, Q10 asked for people's views on the following 8 mechanisms:

1
Continuity with the same health and care professional over time

2
Coordinated joint planning of care and shared decision-making

3
Regular interdisciplinary teamwork including meetings

4
Co-located services in the same building

5
Technology to support continuity and care coordination

6
Specific care coordination roles

7
The availability of shared information/ shared care records

8
Direct involvement of patients and informal carers

Hence, in Q10, respondents were asked to score how advanced each one of these 8 mechanisms is in their own setting, whether that is the service that provides care to them as a user; the service from which the respondent provides care; or the service or system over which the respondent has policy responsibilities or has particular academic or research knowledge.

Finally, in an unstructured, open-text format, the last question (Q11) asked what was the one thing that would make the most difference to coordination and continuity of care in the respondent's setting. This qualitative information was considered complementary to the quantitative data, since it allows to better understand the reasons for the quantitative results and their trends over time.

[15] World Health Organization. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018 [cited 2021 30 August]. Available from: https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y

Study population

The study population consisted of members of IFIC's global network. This network encompasses the more than 23,000 people that were in the IFIC database and distribution list when the survey was launched. This list compiles the people who have participated in ICIC conferences over the years, who have attended our Integrated Care Academy programmes, or those that receive the IFIC bulletin regularly. The extent and diversity of the study population allowed us to obtain a comprehensive view on how coordination and continuity of care is delivered.

The online survey was administrated among the members of IFIC's global network using social media channels, IFIC's newsletter, the International Conference for Integrated Care 2023 (ICIC23) and IFIC's website. Participants were invited to complete the survey designed to collect data on continuity and coordination of care.

Table 1 below illustrates the distribution of participants. We received a total of 683 responses for the English version and 39 for the Spanish version of the survey. Both versions were merged and cleaned, resulting in a total of 662 valid responses. Our sample is split among female, male and non-binary, other and/or prefer not to say, with the 72.1% identifying as female, 26.3% as male, and 1.7% as non-binary, other and/or prefer not to say.

The distribution for age groups follows as 18-29 (5.44%), 30-44 (30.97%), 45-59 (38.52%), 60-75 (22.21%), 75+ (2.42%) and prefer not to say (0.45%).

We categorised respondents according to the 3 roles: users; health and care providers; policymakers or academics. As Table 1 shows, half of respondents were health and care providers (53.8%), followed by policymakers and academics (34.6%). Users accounted for 11.6% of respondents.

Table 3. Respondents profile

Demographic feature	Profile	Profile
Gender		
Female	477	72.1%
Male	174	26.3%
Non-binary | Other | Prefer not to say	11	1.7%
Age		
18 - 29	36	5.44%
30 - 44	205	30.97%
45 - 59	255	38.52%
60-75	147	22.21%
75+	16	2.42%
Prefer not to say	3	0,45%
Role		
User	77	11.6%
Health and care provider	356	53.8%
Policy or academic	229	34.6%

The total 662 respondents were from 65 countries, although the top-5 countries were Canada (119 respondents), Belgium (84), United Kingdom (80), Australia (67) and Ireland (55 respondents).

Data analysis

After collecting data, statistical descriptive analyses were employed for the quantitative data, to summarize and describe the data in a clear and meaningful way. Initial comparisons among different sociodemographic variables were carried out using the mean.

Thematic analysis was used for the open-text format questions (Q9; Q11) by three researchers (AGS, EA and AAR). Illustrative quotes from the responses capturing each theme were used to support the findings of the descriptive analyses.

Key findings

1 Is care continuous and coordinated? The views of Users and Providers

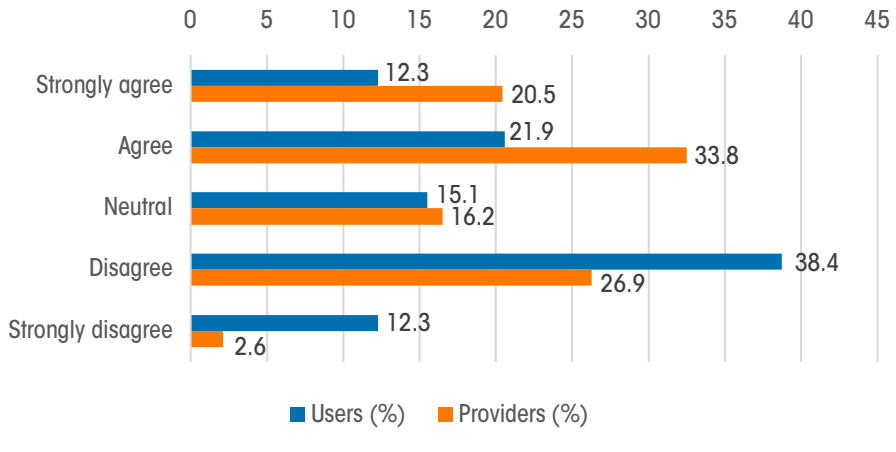
Service users and care providers are more positive about achievements with care continuity than coordination of care: 50.85% of all respondents (both users and providers together) agree (agree and strongly agree) with the view that the care they receive or provide is continuous over time, while 38.55% of all respondents agree (agree and strongly agree) with the view that the care they receive or provide is coordinated across multiple providers and settings.

Service users have a more negative perception than providers on the degree to which care services are done with continuity and in a coordinated manner. Only a third (34.2%) of the users agree with the view that the care they receive is continuous over time in contrast with the views of half of providers (54.3%) who think that the care they provide is indeed continuous.

Table 4. Views of users and providers about care continuity

	Users	Users	Providers	Providers
Strongly agree	9	12.3%	71	20.5%
Agree	16	21.9%	117	33.8%
Neutral	11	15.1%	56	16.2%
Disagree	28	38.4%	93	26.9%
Strongly disagree	9	12.3%	9	2.6%
Total	**73**	**100%**	**346**	**100%**

Views of users and providers about care continuity

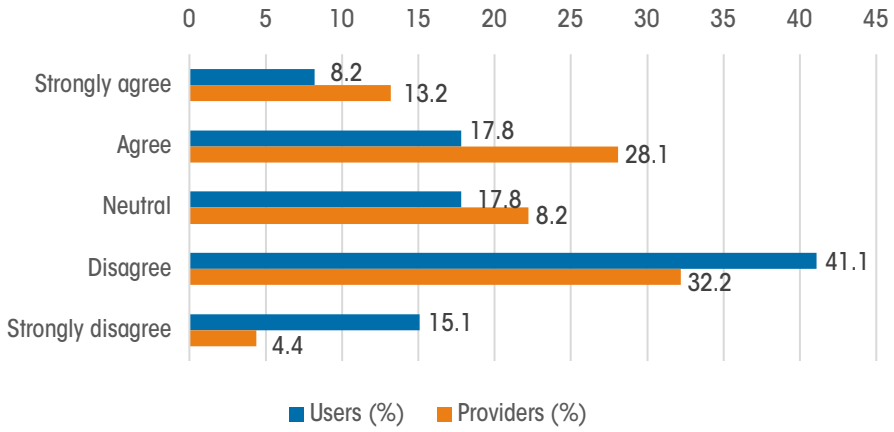


Coordination even scores less sympathy than continuity when looking by groups, with service users having again a more negative perception than care providers. Only a fourth (26%) of the users agree with the view that the care they receive is coordinated in contrast with 41.3% of providers who think that the care they provide is coordinated across multiple providers and settings.

Table 5. Views of users and providers about care coordination

	Users	Users	Providers	Providers
Strongly agree	6	8.2%	45	13.2%
Agree	13	17.8%	96	28.1%
Neutral	13	17.8%	76	22.2%
Disagree	30	41.1%	110	32.2%
Strongly disagree	11	15.1%	15	4.4%
Total	**73**	**100%**	**342**	**100%**

Views of users and providers about care coordination



Respondents were prompted to expand on the prior responses through free text question. The text Box 1 below includes a selection of quotes from users of health and care services (patients and care givers) that help to understand the negative perceptions about whether care services are done with continuity and in a coordinated manner.

Box 1. Quotes from service users

"I have a new primary care practitioner (PCP) who doesn't know my history and only wants to deal with 1-2 issues at a time. Which is difficult as I have many health concerns. I currently see 4 specialists and have been referred to 4 other specialists I see as required. They all communicate back to my PCP but no one in my opinion is looking at the whole picture. And I also have several allied health workers that assist with my healthcare, also two pharmacists. One for my transplant medication which is covered by our government and the other for all other medication. On top of this is managing my health records from differs portals, it's a big job keeping all my data together".

"As a patient it is my experience that care is so restricted by specialty, and acute care is so separate from ongoing community services. At no point am I asked what my preferences are. At no point am I provided with all of the even minimal support that the state has identified as being necessary in my case. I have a voice, the state has no ears"

"I have a family member with intellectual disability (>age 70) with multiple medical issues and taking 14 different medical therapies - never get a cross disciplinary approach to his complex medical needs"

"Our son has multiple mental and physical health diagnoses. Each professional looks at and cares about that part of the body/mind that they have knowledge about. No one brings it all together. There is no mechanism for community living patients to 'ring an alarm bell' (as can happen in hospitals etc) through Code Blue or similar alarm that a situation is serious and deteriorating. Family doctors do not have time, knowledge, expertise or team support to play a coordinating/partnership role with patient/family".

"For someone like myself, who has 7 long-term medical conditions, there is precious little coordination of care and service due to the lack of integrated information between departments and different services. Even my GP surgery can't/won't coordinate my patient notes between different GPs, and I see a different GP every time I request an appointment! This problem is greatly magnified when dealing with different hospital departments, and even worse between different hospitals and social services. There must be a central repository of patient information, so that different departments/hospitals/services can access all relevant information. I am heartily sick of having to answer the same questions, time after time after time, and this certainly wastes time in any appointment. As to continuous care, it's almost impossible due to the lack of staff, in every department and service within the Health and Social Care structure. More funding and recruitment is desperately needed"

Several service users pointed to the fact that **repeating the patient story again and again** is a symptom of poor continuity of care: "speaking as rare disease patient representative, we often have to tell our stories over and over again whenever we need help from the healthcare system"; "I find providers don't talk and share and people need to tell their story over and over again". For service users, **continuity with the same health and care professionals is a challenge** ("I never see same doctor at hospital") and "there is seldom continuity, especially at the transition age from young people to adulthood or adults (including the elderly) who need different help or care".

Above all, the strongest message from a considerable number of service users is that continuity and coordination ultimately fall on them. As quotes from Box 2 reflect, the patient and the family are often the most important real instrument to ensure care continuity and care coordination.

Box 2. Quotes from service users: they are the effective instruments of continuity and coordination

"I am the one in charge or coordination and continuity no one else. The system is organised in a silo type"

"(I have a) chronic arthritic condition that seems to be just up to me to manage"

"Speaking as rare disease patient representative… we and our families have to be the experts and coordinate"

"As a health consumer, the only integration that happens is when I am able to gather all my own health data and present it to the next person / medical professional. Without my input - there would be scattered info everywhere".

"Many times, it's left up to me to share information about appointments with other providers. They should be talking automatically and I should have a record of all my conversations with them in a central place".

"I support mental health care provided to my aged parent residing previously independently at home and currently in supported living setting. The coordination of her care (medication reviews, assessment updates, etc. is heavily reliant on my efforts to retain information, records and to request referrals, coordinate appointments, ensure orders are executed, etc.)"

"I am the person who co-ordinates my care. Appointments, blood tests, chasing referrals, PT, OT. It's up to me to decide and schedule everything. Only incidents are coordinated, like a surgery, and only within the limits that the hospital/surgeon control".

"Unless one is experiencing a life-threatening illness, it is my feeling it is up to the client/patient to do the coordination. This is not a bad thing necessarily, but it feels as though care providers struggle to get a cross disciplinary approach to complex medical needs"

"My experience is that as the 'user', I am the co-ordinator of services delivered to me".

Health and care providers actually recognise this instrumental role of service users: "continuity seems to be hit and miss. Seems to depend on a person's individual ability to ask for help, their means, the availability of services, the strength of the community they live in". However, a repeated message from providers is that they are aware of the importance of care continuity and coordination and are actually making great efforts to achieve it, despite shortcomings (Box 3).

Box 3. Quotes from providers, showing deep commitment to the goals of care coordination and continuity

"I work for a private pay home care provider. As private pay we are locked out of the health care continuum and have no opportunity to provide continuity of care. When we attempt to engage with those in the public sector, we are ignored or dismissed as irrelevant even though we may have a well-established relationship with the client/patient and have valuable information and insights to share"

"All my life, I tried bridging the gaps to provide a holistic care to my patients. However, lack of inter professional education and workforce shortage, poor general and oral health literacy across all stakeholders, absence of policies towards integrated care as standard protocol were major barriers"

"As a leader in a complex system, we identify challenges and barriers in continuous and coordinated care regularly. We are working to improve this. However, I do not yet see that our system supports continuity of care".

"We try to provide coordinate care via the teams but is time consuming and not valued by the system".

"I believe that the services we provide are always based on the intention of meeting patient needs- we continuously look to improve".

"We try to work together, but there is not enough time and not enough employees to do it all the time. There are too few (financial) resources to keep it all the time up to date"

"I think we're trying to provide a continuous and coordinated care. We have multiprofessional teams, including primary and secondary health providers, working for the coordination"

"I feel continuity of care is one of the key elements of care that myself and my team strive"

"I think we are trying our best, but there is still a lot of room for improvement".

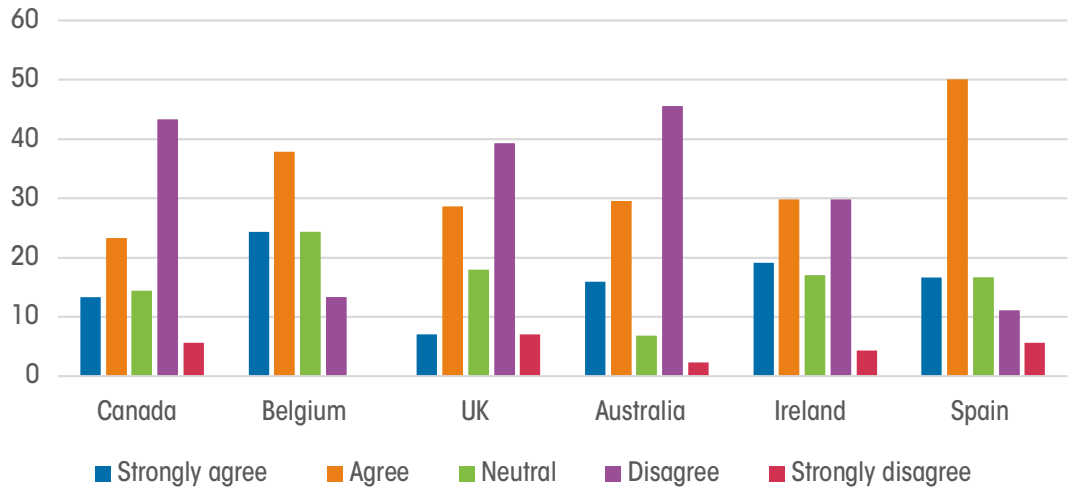
Overall, it seems that providers tend to see **improvements happening at the organisational level rather than at the system level:** "within an organization continuous and coordinated care is more easily managed. Within the broader healthcare system it is still fragmented"; "We operate an integrated primary health team. Services within that team are amazingly continuous and coordinated. The challenge is for referrals and lack of resources outside the agency in spite of strong collaborative linkages".

Results from countries which are otherwise widely regarded as quite advanced in health and care integration (or at least where the integrated care agenda is visible in both research and policy terms) are interesting. As tables 6 and 7 show, the number of users´ and providers´ from Australia, Canada, Ireland and the UK who think that the delivery of care is not continuous and not coordinated across multiple providers and settings is 20 points higher than respondents from Belgium or Spain.

Table 6. Views of users and providers about care continuity (%), by country

	Canada	Belgium	UK	Australia	Ireland	Spain
Strongly agree	13,3%	24,4%	7,1%	15,9%	19,1%	16,7%
Agree	23,3%	37,8%	28,6%	29,5%	29,8%	50,0%
Neutral	14,4%	24,4%	17,9%	6,8%	17,0%	16,7%
Disagree	43,3%	13,3%	39,3%	45,5%	29,8%	11,1%
Strongly disagree	5,6%	0,0%	7,1%	2,3%	4,3%	5,6%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

Views of users and providers about care continuity by country

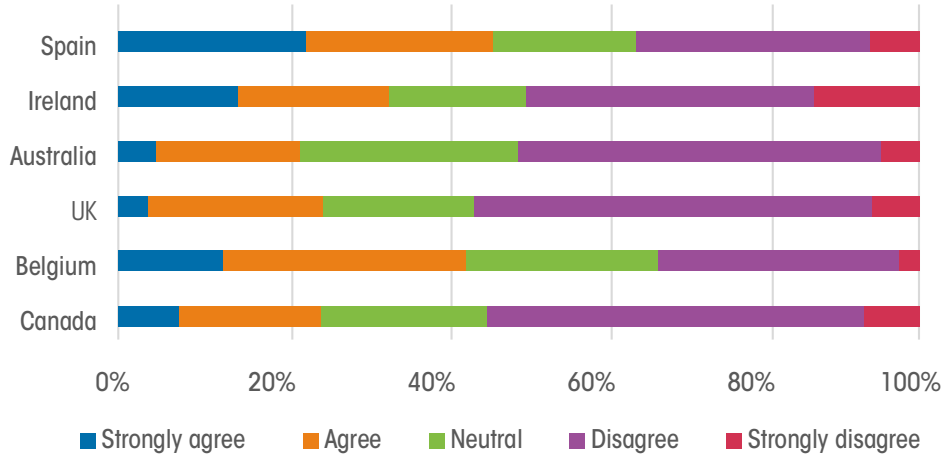


Regarding coordination (Table 7), 77,3% of users and providers from Australia, 74,8% from Canada, 74,1% from the UK and 66% from Ireland disagree (either strongly or just disagree) or were neutral with the view that the care they receive is coordinated across providers and settings, which again contrasts with 56,5% from Belgium or 52,9% from Spain.

Table 7. Views of users and providers about care coordination (%), by country

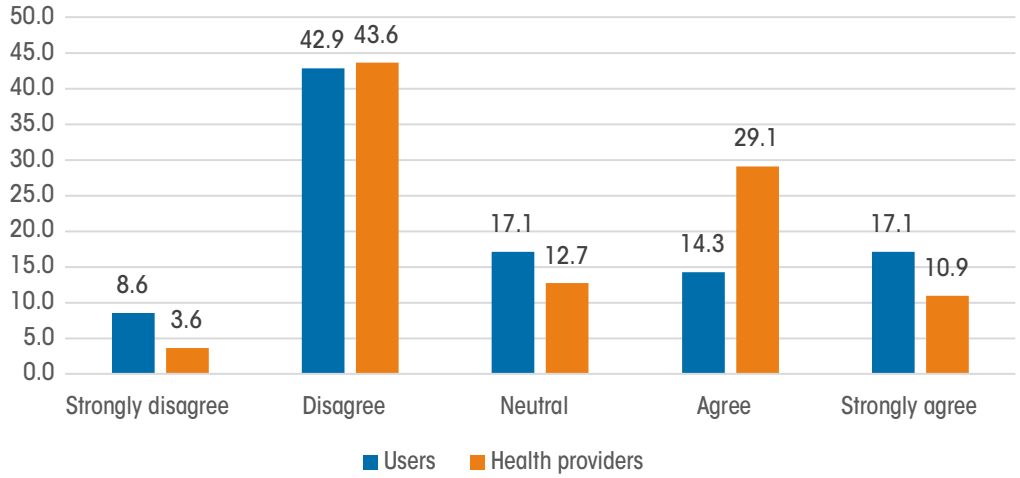
	Canada	Belgium	UK	Australia	Ireland	Spain
Strongly agree	7,7%	13,0%	3,7%	4,5%	14,9%	23,5%
Agree	17,6%	30,4%	22,2%	18,2%	19,1%	23,5%
Neutral	20,9%	23,9%	18,5%	27,3%	17,0%	17,6%
Disagree	47,3%	30,4%	50,0%	45,5%	36,2%	29,4%
Strongly disagree	6,6%	2,2%	5,6%	4,5%	12,8%	5,9%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

Views of users and providers about care coordination by country



The country with the highest number of respondents to this survey, Canada, allows for a comparative analysis of the disaggregated data by users and providers, which reveals similar perceptions: the care received or provided is not continuous over the life course of people.

Canada: users and providers about care continuity (%)

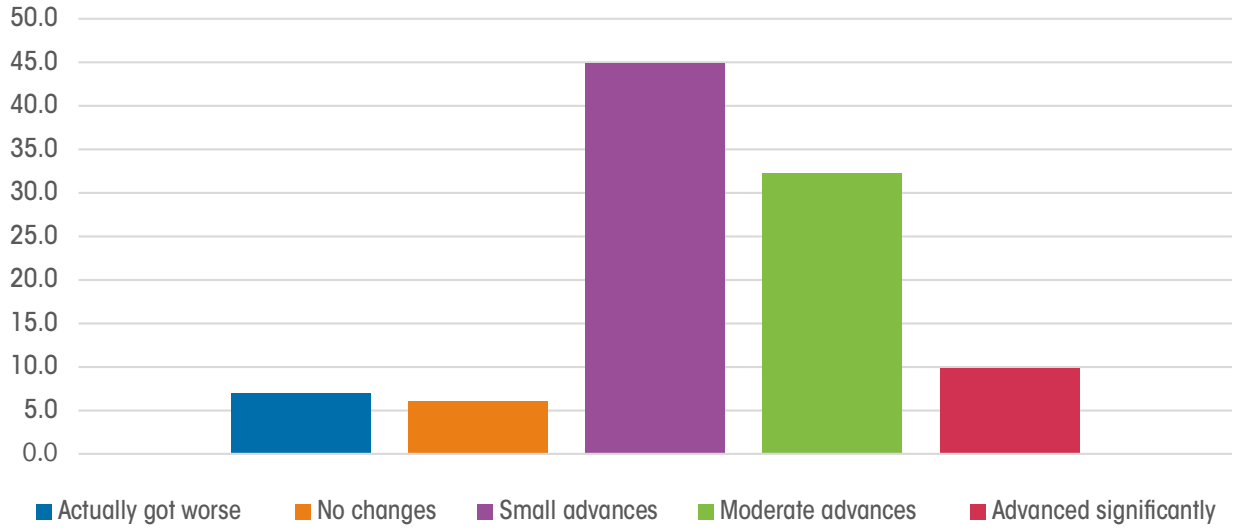


2 How far have we advanced in the provision of continuous and coordinated care? The views of Policymakers and Academics

44.9% of policymakers and researchers feel that there have just been small advances over the past five years. Added to those who consider that there have been moderate advances, 77.1% think that there has been progress in care coordination and continuity over the past 5 years. On the extremes, those feeling that we have advanced significantly exceeds those who think that it has actually got worse - 9.8% versus 7%.

	Policymakers	Policymakers %
Advanced significantly	21	9.8%
Moderate advances	69	32.2%
Small advances	96	44.9%
No changes	13	6.1%
Actually got worse	15	7.0%
Total	**214**	**100%**

Continuous & Coordinated Care



Free text responses reinforce this view on the small and moderate progress, as revealed by the "number of initiatives (implemented) but not consistently across country", while "still much progress to be made". A selection of quotes along this line of argument is provided below:

Box 4. Quotes from policymakers and academics, reflecting the idea of small progress has happened but still much room for improvement

"Trying to induce change, but still on the CEO-organizational level, not yet fully changing on all levels"

"Integration of care is not yet applied on the overall system and remain focus on pilot project"

"Continuous and coordinated care have not improved in practice, however there is increased political and professional attention addressing this"

"I was hesitant to say it has gone backwards, but some days it feels like it. We are talking about the same problems and engage the same people with the same thinking to try to solve it. Transformation is going to require transformative thinking - with the commitment to follow through when it's hard"

"Studies and surveys indicate that care providers and professionals are more convinced of the interest of care continuity and coordination. There are signs of a new culture of integration. Experiments and local initiatives towards care integration may exist. Yet, however, effective integration has not improved"

"When you look at services there are pockets of advancement - whether it be an intervention or a policy but when you talk to people with lived experience about what is important to them or what they need, it becomes apparent that we haven't made strides significant enough to change peoples' experiences"

"My experience is that as the 'user', I am the co-ordinator of services delivered to me"

"There are some pockets of good work but this has been the case for the last 10-20 years. There is a challenge with regards to translating good legislation into consistently good practice"

"I see more awareness of the need to coordinate care, but I am not sure policy is always supporting this. Funding is often patchy (several exclusion criteria), not long term and seldom able to really deliver on health outcomes that matter to people in the community. This is largely caused by the complicated funding landscape and difficulty in co-commissioning".

This perception of slow-progress **is widespread across participants coming from different countries of the globe:**

Nigeria
"except in few areas such as HIV services, providers still work in silos despite recognition of the value of care coordination for a given set of patients and/or populations"

Chile
"changes are still embryonic and highly dependent on local innovation"

Canada
"there is a big appetite for integrated care and care coordination in a Canadian Health System. Health care providers, patients/caregivers, and policy makers are interested in implementing integrated care and ensuring care is coordinated and continuous. However, its implementation at its infancy"

Slovenia
"there are ideas that circle around, some of them implemented into practice, major decision makers are stuck in traditional mindsets"

Singapore
"there are a number of initiatives but not consistent across country, still much progress to be made"

Several respondents mentioned the effect of the COVID-19 pandemic on the move towards more continuous and coordinated care, considering that its effects might have been either positive or negative. Indeed, for many the COVID-19 pandemic has been a catalyst: "In the last 5 years lot of things changed in care. COVID made it change faster. In Belgium a lot of 'projects' came and we have our 'eerstelijnszones' who made everything in the direction of integrated care, connecting with each other"; "there has been some great innovations and progress especially in the context of COVID response and utilising virtual care and attempting to deliver high quality care in the community to reduce ED burden"; "the global pandemic brought inequity sharply into focus. In my field of integrated service delivery in child and family support that triggered renewed efforts to improve integrated services".

On the other hand, for many policymakers and researchers, **COVID-19 might have slowed or halted progress:** "Progress has been hindered due to the global Covid-19 restrictions: in the post Covid-19 restrictions era, there are more opportunities for health and social care organisations to resume the work of developing continuous and coordinated care"; "COVID had an impact on the workforce with affected coordination and continuity"; "Covid pandemic slowed many changes down", "austerity and the pressures of the backlog from COVID have made joint working harder".

Arguably, COVID-19 has probably had both concurring effects, as one respondent noted: "the pandemic exacerbated the problems that already existed but forced everyone across the care system to realize we needed to do better which led to the development of more virtual care services and integrated care programs".

3 Mechanisms for care continuity and coordination: how much have we advanced?

Survey respondents were asked to what extent there had been advancement in deploying the mechanisms that the literature has suggested as instrumental in the successful provision of continuous and coordinated care. In the following subsections the results linked to the WHO dimensions are presented.

1. Continuity with the same health and care professional over time

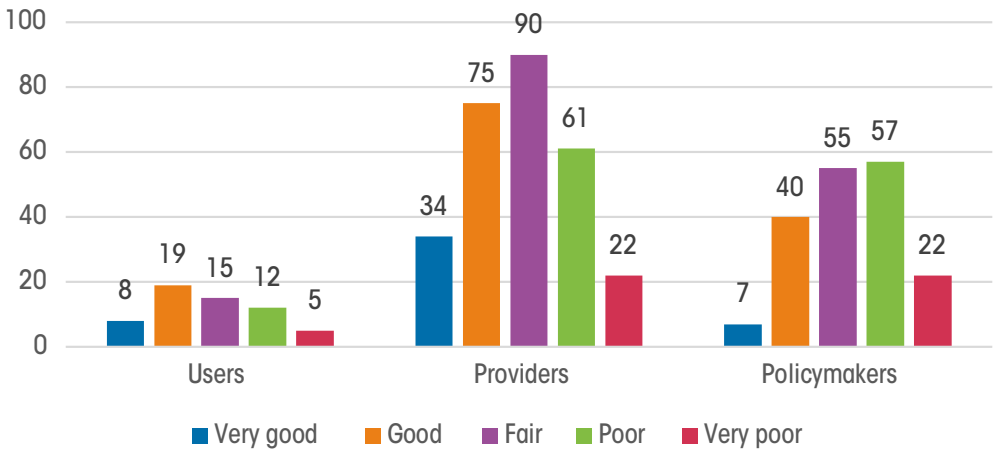
Research suggests that people who have continuous contact with their usual primary care provider have fewer attendances and admissions to an emergency department for conditions requiring ambulatory care and are more satisfied with their care[16]. A recent registry-based observational study in Norway has shown that the length of regular general practitioner and patient relationship is significantly associated with a lower use of out-of-hours services, fewer acute hospital admissions, and lower mortality[17].

In this regard, policymakers and researchers have more negative views on whether there have been advancements in the continuity with the same health and care professional over time, while users and providers score quite similarly. Thus, only 26% of policymakers and researchers believe that advancements in this mechanism have been very positive (seeing either good or very good advancements), while this goes up to 45.8% of users and 38.7% of providers.

Table 9. Views about continuity with the same health and care professional over time, by group

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	8	13.6%	34	12.1%	7	3.9%
Good	19	32.2%	75	26.6%	40	22.1%
Fair	15	25.4%	90	31.9%	55	30.4%
Poor	12	20.3%	61	21.6%	57	31.5%
Very poor	5	8.5%	22	7.8%	22	12.2%
Total	**59**	**100%**	**282**	**100%**	**181**	**100%**

Continuity with the same healthcare professional over time



[16] Chan KS, Wan EYF, Chin WY et al. Effects of continuity of care on health outcomes among patients with diabetes mellitus and/or hypertension: a systematic review. BMC Family Practice [serial online] 2021; 22:145. [cited 2023 Aug 30]. Available from: https://doi.org/10.1186/s12875-021-01493-x

[17] Sandvik H, Hetlevik Ø, Blinkenberg J, Hunskaar S. Continuity in general practice as predictor of mortality, acute hospitalisation, and use of out-of-hours care: a registry-based observational study in Norway. Br J Gen Pract 2022; 72: e84–90. [cited 2023 Aug 30]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8510690/pdf/bjgpfeb-2022-72-715-e84.pdf

2. Coordinated joint planning of care and shared decision-making

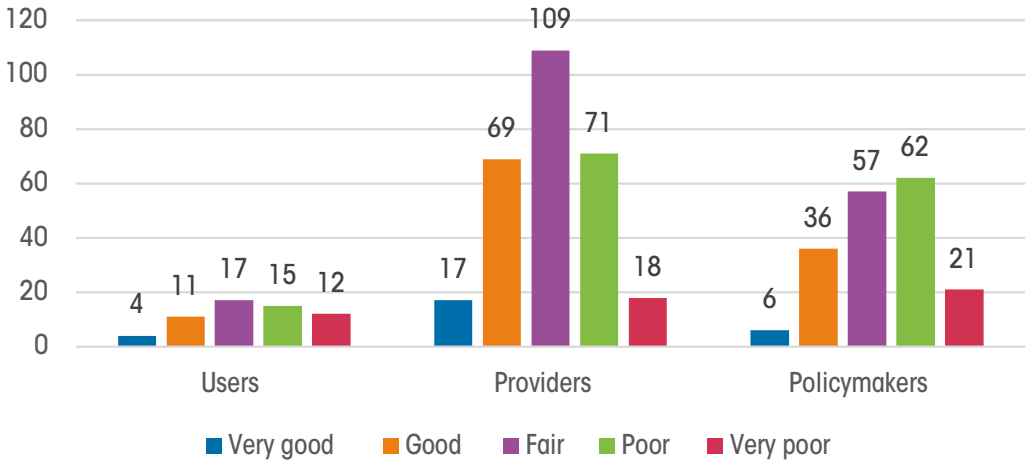
Collaborative planning of care and shared decision-making, in the context of having person-centred, goal-oriented planning of care and coaching that enables individuals, families and informal caregivers to be fully involved in assessment and decisions about care is a factor in successful care coordination[18].

Among users the majority found the advancements in the coordinated joint planning of care and shared decision-making very poor to fair (74.5%), policymakers had a negative opinion from very poor to fair (76.9%) and providers had a more neutral opinion (69.7% from very poor to fair, of which 38.4% said there have been fair advancements).

Table 10. Views of the three groups about coordinated joint planning and shared decision-making

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	4	6.8%	17	6%	6	3.3%
Good	11	18.6%	69	24.3%	36	19.8%
Fair	17	28.8%	109	38.4%	57	31.3%
Poor	15	25.4%	71	25%	62	34.1%
Very poor	12	20.3%	18	6.3%	21	11.5%
Total	**59**	**100%**	**284**	**100%**	**182**	**100%**

Coordinated care planning and joint decision making



[18] Steele Gray C, Grudniewicz A, Armas A, Mold J, Im J, Boeckxstaens P. Goal-Oriented Care: A Catalyst for Person-Centred System Integration. International Journal of Integrated Care [serial online]. 2020 Nov 4;20(4):8. [cited 2023 Aug 30]. Available from: doi: 10.5334/ijic.5520.

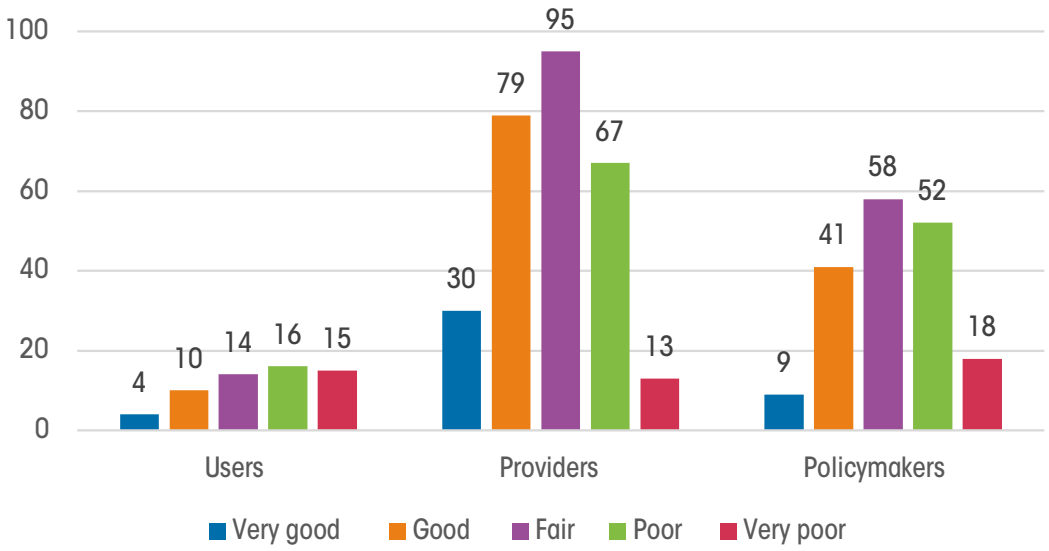
3. Regular interdisciplinary teamwork including meetings

Interdisciplinary teamwork is central to achieving integrated care, in this regard the literature shows that interdisciplinary teamwork for patients with different conditions can reduce unplanned health service utilization, as well as improve quality of life[19]. It's very interesting that more than the half of users (52,5%) think that interdisciplinary team (IDT) work is "poor or very poor", compared to providers (just 28.2%).

Table 11. Views of the three groups about regular interdisciplinary teamwork

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	4	6.8%	30	10.6%	9	5.1%
Good	10	16.9%	79	27.8%	41	23.0%
Fair	14	23.7%	95	33.5%	58	32.6%
Poor	16	27.1%	67	23.6%	52	29.2%
Very poor	15	25.4%	13	4.6%	18	10.1%
Total	**59**	**100%**	**284**	**100%**	**178**	**100%**

Regular interdisciplinary work including meetings



[19] Brennan EJ. Chronic heart failure nursing: integrated multidisciplinary care. British Journal of Nursing [serial online]. 2018 Jun 28;27(12):681-688. [cited 2023 Aug 30]. Available from: doi: 10.12968/bjon.2018.27.12.681.; Jiang W, Zhang Y, Yan F, et al. 2020. Effectiveness of a nurse-led multidisciplinary self-management program for patients with coronary heart disease in communities: A randomized controlled trial. Patient Education and Counseling 103(4): 854-63. [cited 2023 Aug 30]. Available from: https://doi.org/10.1016/j.pec.2019.11.001

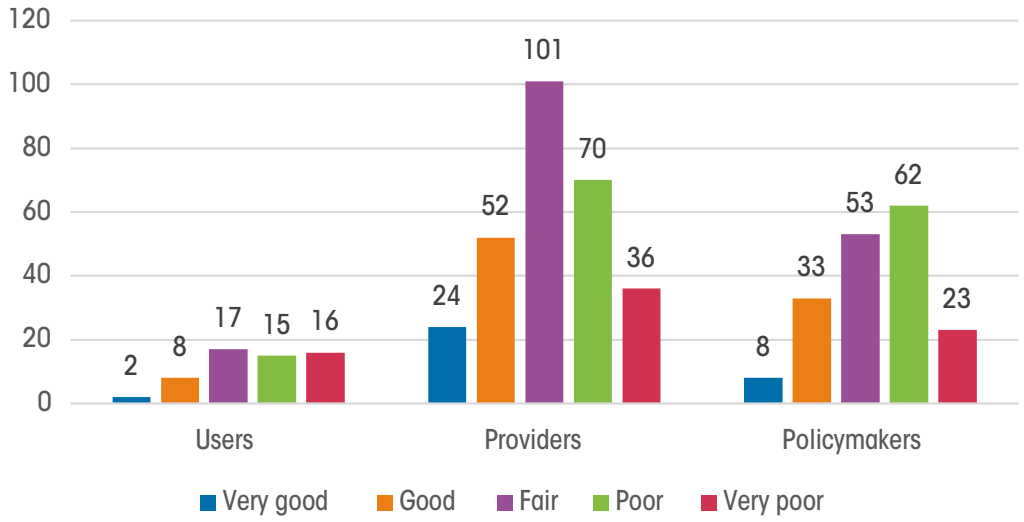
4. Co-located services in the same building

Collocation of different professionals, providers and services and links with people who know local community and voluntary resources helps people who require chronic care to navigate and access the services and community support they need[20]. Providers and policymakers have a similar opinion with middle to high expectations (very poor: providers 12.7%, policymakers: 12.8%; poor: providers 24.7%, 34,6%; fair: providers 18.4%, policy makers: 18.4%; and very good: providers 8.5%, policymakers 4.5%), having slightly higher opinions the providers group, while users are more pessimistic regarding the advancements in this mechanism (82% from very poor to fair).

Table 12. Views of the three groups about co-located services in the same building

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	2	3.4	24	8.5	8	4.5
Good	8	13.8	52	18.4	33	18.4
Fair	17	29.3	101	35.7	53	29.6
Poor	15	25.9	70	24.7	62	34.6
Very poor	16	27.6	36	12.7	23	12.8
Total	**58**	**100%**	**283**	**100%**	**179**	**100%**

Colocated services in the same building



[20] Hammer JH, Perrin PB, Spiker DA. Impact of integrated care and co-location of care on mental help-seeking perceptions. Journal of Ment Health. 2021 Aug; 30(4):405-410. [cited 2023 Aug 30]. Available from: doi: 10.1080/09638237.2019.1581334

5. Technology to support continuity and care coordination

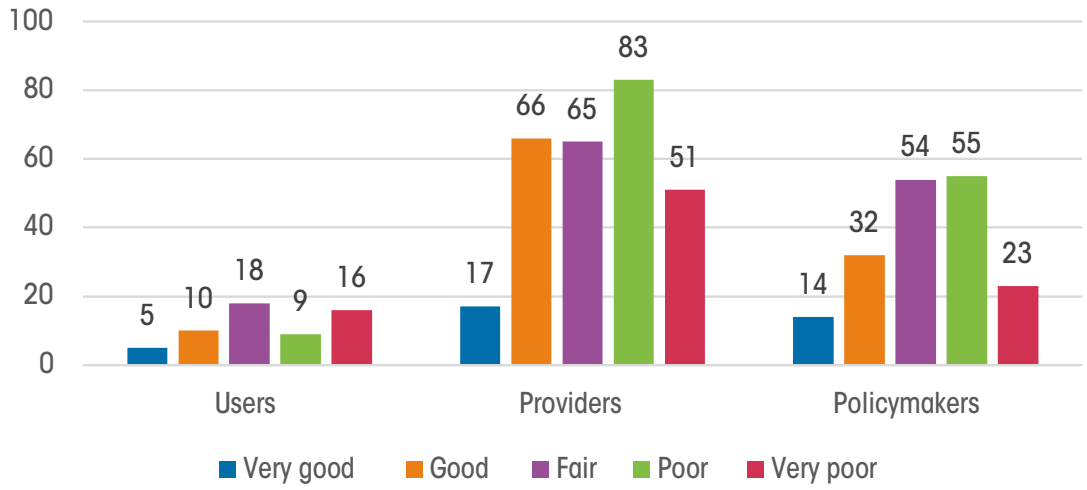
Technology to support continuity and care coordination allows to cross the boundaries of sectors and organisations between health and social care and supports independent living and home care. Tools and platforms for the exchange of information facilitate adoption of practice interventions and identification of people who have multiple conditions, complex circumstances or have the most to gain from care coordination[21].

In this regard, providers have the lower opinion (between very poor and poor) regarding the technological advancements supporting continuity and care coordination, following policymakers (43.8%) and users (43.1%). These high percentages show dissatisfaction with the available technologies supporting continuity and care coordination.

Table 13. Views of the three groups about technology to support continuity and care coordination

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	5	8.6	17	6	14	7.9
Good	10	17.2	66	23.4	32	18
Fair	18	31	65	23	54	30.3
Poor	9	15.5	83	29.4	55	30.9
Very poor	16	27.6	51	18.1	23	12.9
Total	**58**	**100%**	**282**	**100%**	**178**	**100%**

Technology to support continuity and care coordination



[21] Baltaxe E, Czypionka T, Kraus M, Reiss M, Askildsen JE, Grenkovic R, Lindén TS, Pitter JG, Rutten-van Molken M, Solans O, Stokes J, Struckmann V, Roca J, Cano I. Digital Health Transformation of Integrated Care in Europe: Overarching Analysis of 17 Integrated Care Programs. Journal of Medical Internet Research. 2019 Sep 26;21(9):e14956. [cited 2023 Aug 30]. Available from: doi: 10.2196/14956

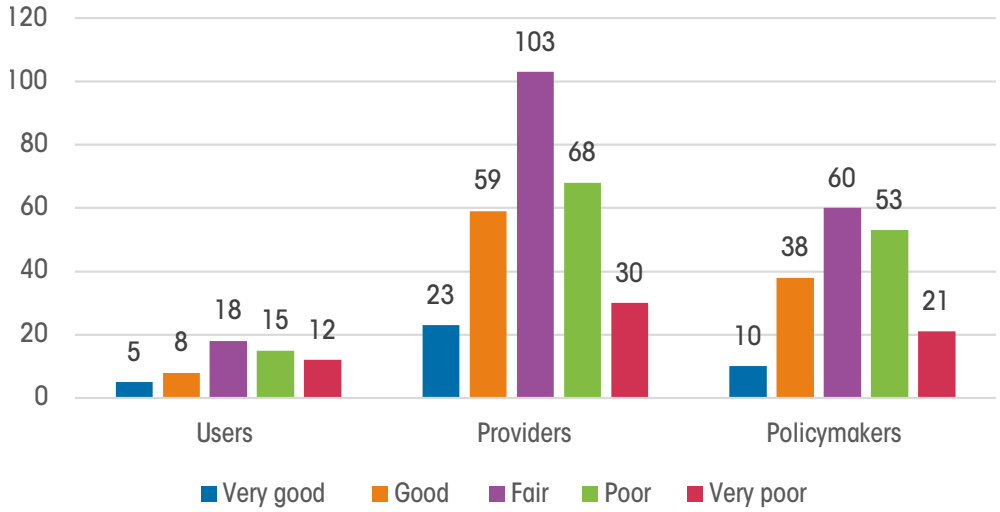
6. The deployment of specific care coordination roles

The deployment of new specific care coordination roles (e.g., case managers, patient navigators. care coordinators, discharge coordinators, etc.) facilitating the coordination and continuity of care for individuals[22]. The advancements in this mechanisms are perceived lower by users (76.6% between very poor and fair), than providers and policymakers which see fair to very good with 52.9% and 59.4% respectively.

Table 14. Views of the three groups about the deployment of specific care coordination roles

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	5	8.6	23	8.1	10	5.5
Good	8	13.8	59	20.8	38	20.9
Fair	18	31	103	36.4	60	33
Poor	15	25.9	68	24	53	29.1
Very poor	12	20.7	30	10.6	21	11.5
Total	**58**	**100%**	**283**	**100%**	**182**	**100%**

The deployment of specific care coordination roles



[22] European Observatory on Health Systems and Policies, Winkelmann J, Scarpetti G, Williams GA, Maier CB. How can skill-mix innovations support the implementation of integrated care for people with chronic conditions and multimorbidity?. Copenhagen: World Health Organization. Regional Office for Europe; 2022. [cited 2023 Aug 30]. Available from: https://apps.who.int/iris/handle/10665/358467

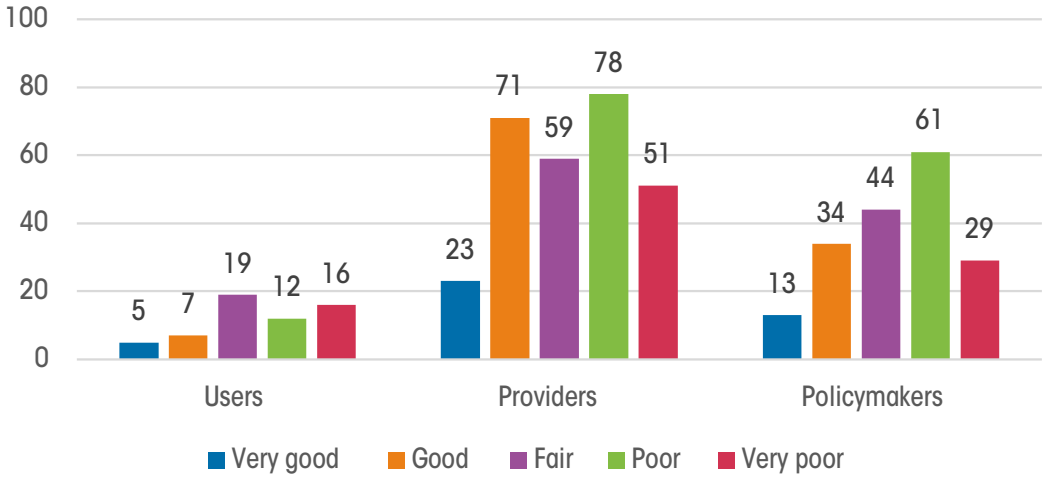
7. The availability of shared information / shared care records

The availability of shared information/shared care records allow the seamless flow of information among key stakeholders in the web of care in the community, including the person and their caregivers . User have lower opinions regarding the advancements in this mechanism 79.6% from very poor to fair, while providers and policymakers having a slightly more positive views of the advancements in this, being a bit higher the opinion of the providers.

Table 15. Views of the three groups about the availability of shared information / shared care records

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	5	8.5	23	8.2	13	7.2
Good	7	11.9	71	25.2	34	18.8
Fair	19	32.2	59	20.9	44	24.3
Poor	12	20.3	78	27.7	61	33.7
Very poor	16	27.1	51	18.1	29	16
Total	**59**	**100%**	**282**	**100%**	**181**	**100%**

The availability of shared information/shared care records



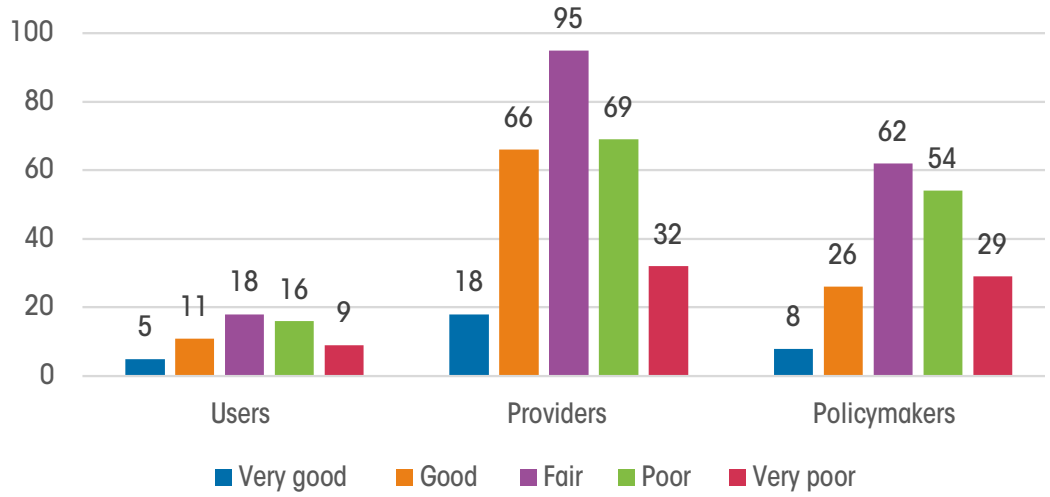
[23] Cresswell K, Anderson S, Mozaffar H, Elizondo A, Geiger M, Williams R. Socio-Organizational Dimensions: The Key to Advancing the Shared Care Record Agenda in Health and Social Care. Journal of Medical Internet Research. 2023 Jan 26;25:e38310. [cited 2023 Aug 30]. Available from: doi: 10.2196/38310. PMID: 36701190; PMCID: PMC9912150.

8. Direct involvement of patients and informal carers in care planning and delivery

Direct involvement of patients and informal carers in care planning and delivery allows the transparency and the enough knowledge for patients and carers to better understand and navigate health and care systems in their care process[24]. Providers have the most positive view in this regard, followed by users. Contrary, policymakers and researchers have lower opinions on the advancements in this mechanism.

	Users	Users %	Providers	Providers %	Policymakers	Policymakers %
Very good	5	8.6	23	8.1	10	5.5
Good	8	13.8	59	20.8	38	20.9
Fair	18	31	103	36.4	60	33
Poor	15	25.9	68	24	53	29.1
Very poor	12	20.7	30	10.6	21	11.5
Total	**58**	**100%**	**283**	**100%**	**182**	**100%**

Direct involvement of patients and informal carers in care planning and delivery



[24] Vanstone M, Canfield C, Evans C, Leslie M, Levasseur MA, MacNeil M, Pahwa M, Panday J, Rowland P, Taneja S, Tripp L, You J, Abelson J. Towards conceptualizing patients as partners in health systems: a systematic review and descriptive synthesis. Health Research Policy and Systems [serial online] 2023 Jan 25;21(1):12. [cited 2023 Aug 30]. Available from: doi: 10.1186/s12961-022-00954-8

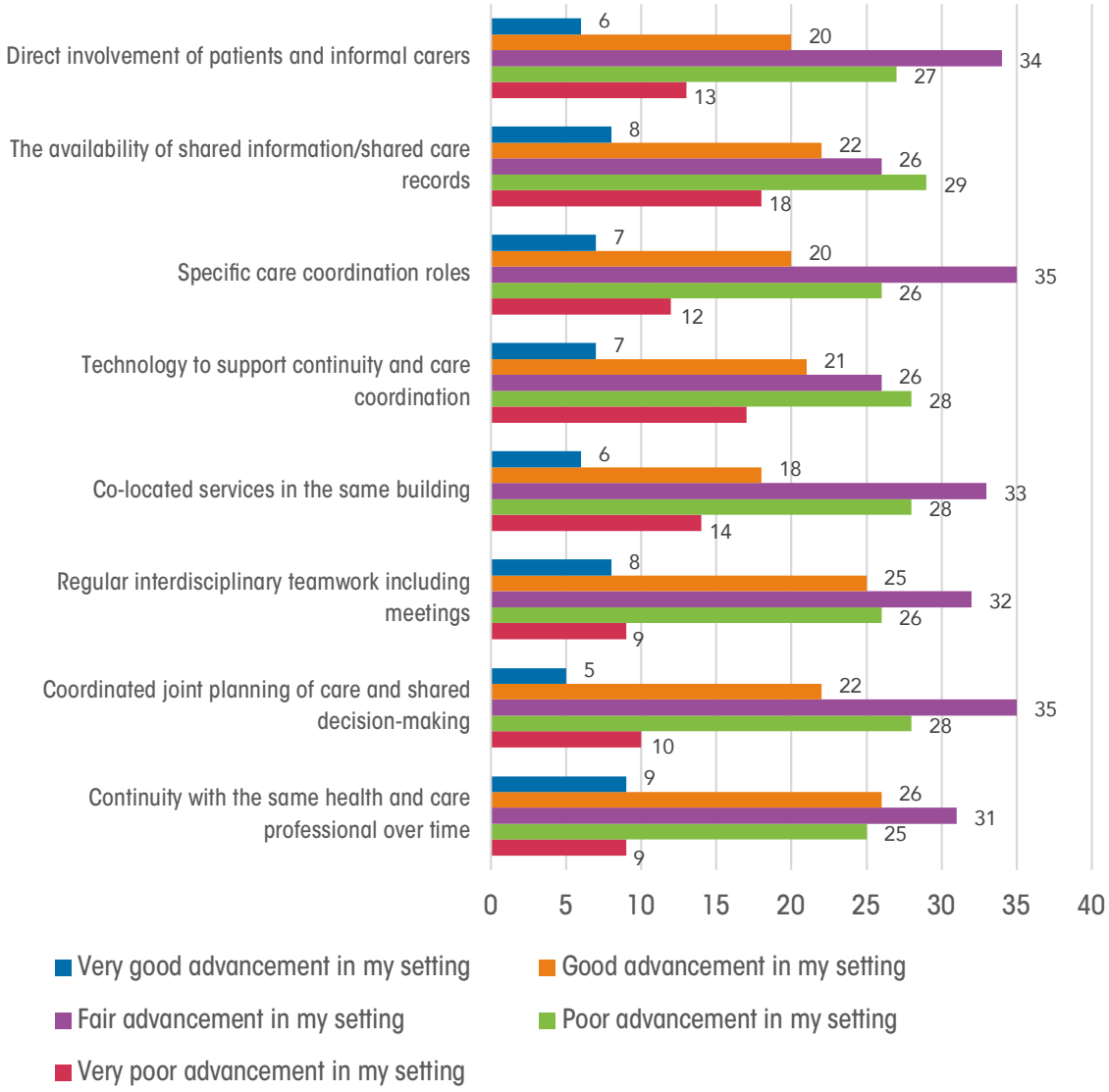
Any one mechanism to make the most difference?

Taking all respondents together, none of the 8 mechanisms is perceived as having made positive (either "good" or "very good") advancements. At the top of the list, 35.1% of respondents believe that "Continuity with the same professional" has made good and very good advancements, followed by "Regular interdisciplinary team meetings" with 33.2% of respondents believing so. The rest of the mechanisms fall below 30%, with the co-location of services at the bottom.

	Very poor advancement in my setting	Poor advancement in my setting	Fair advancement in my setting	Good advancement in my setting	Very good advancement in my setting	Combined good and very good
Continuity with the same health and care professional over time	9.4%	24.9%	30.7%	25.7%	9.4%	35.1%
Coordinated joint planning of care and shared decision-making	9.7%	28.2%	34.9%	22.1%	5.1%	27.2%
Regular interdisciplinary teamwork including meetings	8.8%	25.9%	32.1%	25.0%	8.3%	33.2%
Co-located services in the same building	14.4%	28.2%	32.8%	17.9%	6.5%	24.4%
Technology to support continuity and care coordination	17.4%	28.4%	26.4%	20.8%	6.9%	27.8%
Specific care coordination roles	12.2%	26.3%	34.9%	20.3%	7.3%	27.6%
The availability of shared information/shared care records	18.5%	29.2%	23.6%	21.6%	7.9%	29.5%
Direct involvement of patients and informal carers	13.5%	26.8%	33.8%	19.9%	6.0%	25.9%

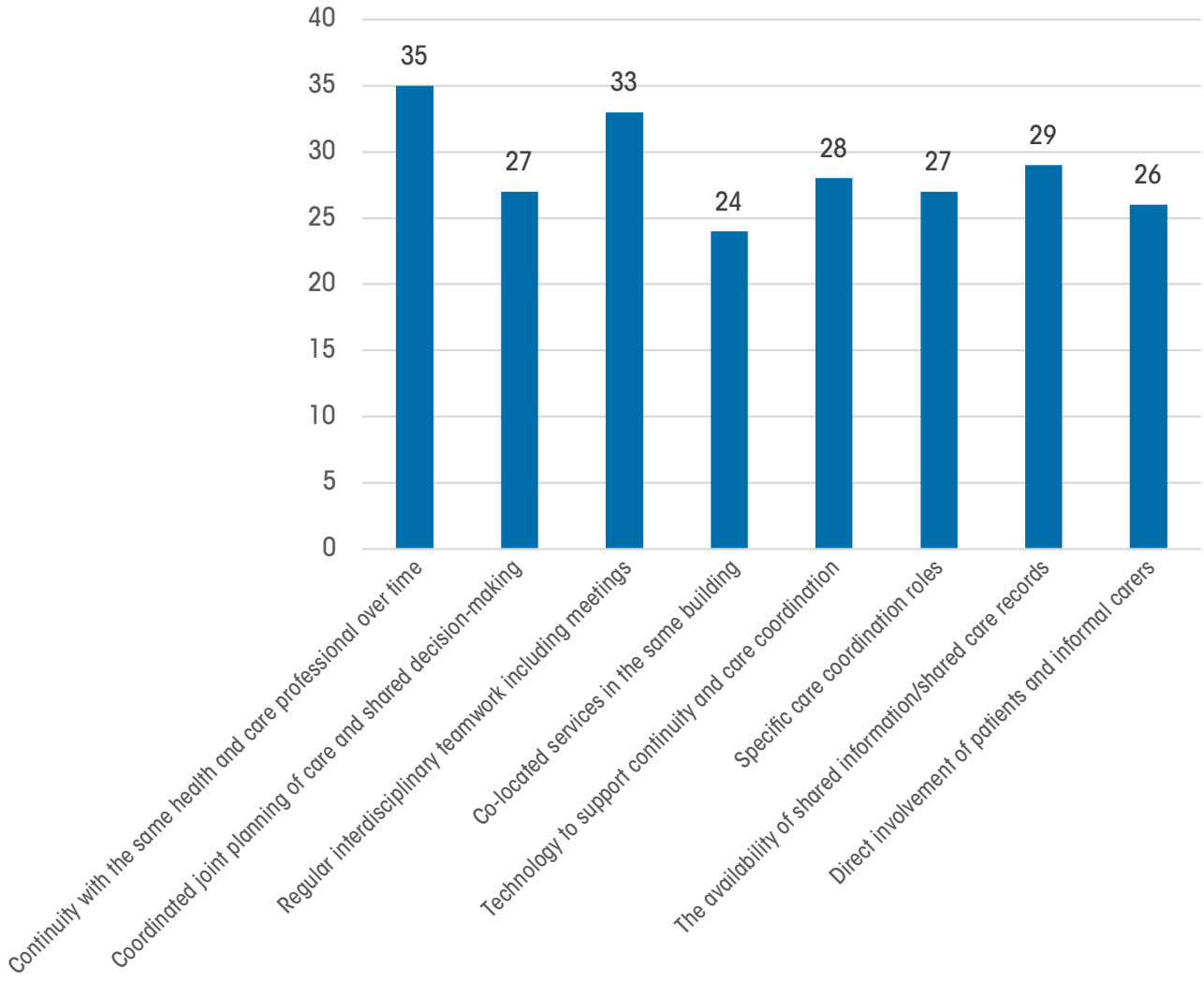
By group, service users' views of "Continuity with the same professional" scores the highest positive rate (45.8%) (combining good and very good) for all 8 mechanisms and across all 3 groups. This however contrast with policymakers, with only 26% of them believing that good and very good advancements have been achieved on this specific mechanism of maintaining continuity with same professionals.

Comparative overview



Regarding the rest of mechanisms and compared to the other 2 groups, **service users hold the most critical views** (the highest percentage of those voting fair, poor or very poor) on "Regular interdisciplinary team meetings" (76.2%), "Co-located services" (82.2%), "Technology to support coordination" (74.1%), "Coordination roles" (77.6%) and "Availability of shared information" (79.6%). **Policymakers are the highest critics** about advancements with "Continuity with the same professional" (74.1%), "Coordinated joint planning" (76.9%) and "Direct involvement of patients" (81%).

Combined good and very good %



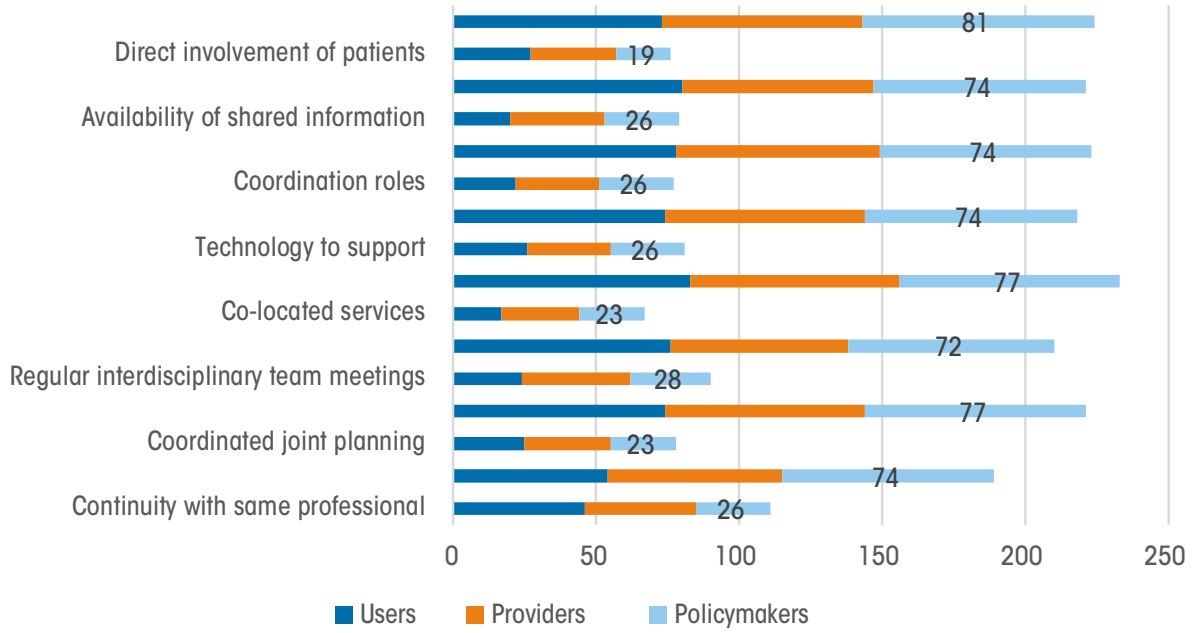
Providers, however, do not stand out much as the most critical on any mechanism but instead consistently hold the highest consideration of advancements on all mechanisms, apart from "Continuity with same professional", that is the best viewed by service users.

Mechanism		Users	Providers	Policymakers
Continuity with same professional	Good+VG	45.8	38.7	26
	Fair+Poor+VP	54.2	61.3	74.1
Coordinated joint planning	Good+VG	25.4	30.3	23.1
	Fair+Poor+VP	74.5	69.7	76.9
Regular interdisciplinary team meetings	Good+VG	23.7	38.4	28.1
	Fair+Poor+VP	76.2	61.7	71.9
Co-located services	Good+VG	17.2	26.9	22.9
	Fair+Poor+VP	82.8	73.1	77
Technology to support	Good+VG	25.8	29.4	25.9
	Fair+Poor+VP	74.1	70.5	74.1
Coordination roles	Good+VG	22.4	28.9	26.4
	Fair+Poor+VP	77.6	71	73.6
Availability of shared information	Good+VG	20.4	33.4	26
	Fair+Poor+VP	79.6	66.7	74
Direct involvement of patients	Good+VG	27.1	30	19
	Fair+Poor+VP	72.9	69.9	81

Respondents were prompted to expand on the prior responses and describe in a free text "the one thing that would make the most difference to coordination and continuity of care in your setting".

Many respondents approached this by referring to the mechanisms listed in the previous question and prioritising one or various over the others. By far, **"the availability of shared information/shared care records"** surfaced as the mechanism which would make the most difference, followed by **"regular interdisciplinary teamwork"**, "technology" in general (referring to platforms and other IT tools to support continuity and care coordination" and **"specific care coordination roles"**. Many respondents included more than one mechanism in their responses actually, which can reflect the thinking that care coordination and continuity requires addressing multiple actions and levers at the same time.

Aggregating Good and Very Good, compared by Fair, poor and very poor, by dimension of analysis



"The availability of shared information/shared care records" was most valued by all groups, particularly for users and providers. Respondents referred to the various dimensions included in this category: "electronic health records"; "Integrated electronic health record and care management system "various health providers can access patient information", including "access to real time data"; "various services to communicate and use same assessment and recording platforms"; "shared medical record with patient and caregiver access".

Box 5. Selection of quotes on the availability of information/shared care

"A functioning electronic patient record implemented across areas and shared with patients. If patients held their own records, it would provide continuity and save duplication. Empowering and respecting the patients voice is key".

"There is a lot of discourse regarding integrated care and informatics. It is very unrealistic on the frontline due to many different IT services. There should be an identifier that's specific to a patient and all the systems link but that's not happening in reality"

"Our healthcare system would benefit from access to portable electronic documentation where a care provider is able to document at the bedside or in a patient's home while supporting patients in their own home environment. Also, I wish our patient records were easily accessible to care providers in all settings. We have only partially accomplished this goal".

"Whereas our services are integrated, client data on our electronic medical record system is fragmented. The data might reside in the system but accessed at different sections which results in gaps during patient review. For example, a HIV positive client coinfected with COVID19 or tuberculosis (TB). On review, if data for covid19 is accessed from a different form, it is very easy to miss out on the coinfection affecting the patient"

"Regular interdisciplinary teamwork" responses also touched on a number of interesting (and contradictory) aspects, probably reflecting that it is a work in progress in most systems, as Box 6 show:

Box 6. Selection of quotes on regular interdisciplinary teamwork

"Working together - being able to span boundaries of interprofessional teams and truly come together to make a difference".

"Regular interdisciplinary teamwork including time for planned meetings".

Opposing views on the contribution of co-location to interdisciplinary work:

"We now have managed interdisciplinary teams effectively, but it took a long time - shared office space would and still could make a difference".

"More shared information and linkages between paramedic services and other community providers and primary care. Note that co-location of services in the same building is really not relevant when you're talking the context of bringing the care to the patient (vs making the patient come to care) - technological solutions to being the multidisciplinary team into the home are needed".

Perception is that working in teams is not incentivised or valued:

"We try to coordinate care via the teams but (it) is time consuming and not valued by the system".

"Too many handoffs, different commissioning arrangements, lack of shared electronic health records, no incentives to join up. Pressure and perceived efficiency favour episodic responsive care and not proactive".

A few respondents mentioned **time** as the key variable (Box 7). Time would be a precious resource and "taking the time to know their patient" would be a mechanism to enhance care continuity and coordination[25]. Interestingly, this was mentioned by both users and providers, but not by any policymaker or academic.

[25] We wrote about time as a key condition for integrated care in an IFIC blog: IFIC. Time is what the health workforce mostly need [webpage on the internet] 2022 April 7. [cited 2023 Aug 30]. Available from: https://integratedcarefoundation.org/blog/world-health-worker-week-april-4-8-2022build-the-health-workforce-back-better

Box 7. Selection of quotes from all respondents, on the need for time

"More doctors who have the time to listen to patients and 15 minutes is not enough. Put a cap on how many patients a doctor can see in a day and have time to communicate with other professionals involved in the patient's care include the patient as well at the table" [user]

"More time to spend with patients, less pressure to see several patients per day for short periods of time" [provider].

"Taking the time to know their patient" [user]

"Time to care instead of limit time to a break even cost versus income balance" [provider].

"More time to have a more personal contact with the patients" [provider]

Other respondents chose to approach the question by referring to the elements that may enable or otherwise block the advancement of care coordination and continuity. Indeed, these are system factors rather than specific interventions, tools or approaches. For example, resources (either money, workforce or medicines available) is an essential precondition for the performance of the care system(s): so why it is obvious the need for it, it however has a less direct effect on care coordination and continuity.

To help structure the analysis, we grouped all these responses within **IFIC's 9 Pillars of Integrated Care**[26].

Hence, the pillars most noted by respondents were, in order:

1
System wide governance and leadership

2
Shared values and vision

3
Aligned payment systems

4
Workforce capacity and capability

Indeed, funding – the need for more funding- was indeed mentioned by many respondents but only a few pointed however to specific payment arrangements that would be instrumental on promoting coordination/continuity: pool budgets; grants; bundled payments; financial incentives.

[26] The 9 Pillars of Integrated Care is conceptual framework developed by IFIC, to navigate any system´s journey in delivering coordinated, continuous, person- and community-centred integrated care: 1) shared values and vision; 2) population health and local context; 3) people as partners in care; 4) resilient communities and new alliances; 5) workforce capacity and capability; 6) System wide governance and leadership; 7) digital solutions; 8) aligned payment systems; and 9) Transparency of progress, results and impact. https://integratedcarefoundation.org/nine-pillars-of-integrated-care

Box 7. Selection of quotes from all respondents

On governance

"There are too many authorities, administrations, organisations that are involved, so it's not easy for the provider neither for the receiver to find their way in this tangle, to find out what's possible... Sometimes it's not only a question of money"

"During pandemic great advances were made quickly, now however the command-and-control regime remains and so joint working and connection with colleagues in other sectors very challenging. Culture has moved to risk aversion and suspicion"

"The system blocks local initiatives through bureaucracy and through inflexible tools that govern and support local structures"

On (lack of) shared values

"Services, departments and divisions do not communicate with each other regarding on going care and treatment of our individuals. No one makes any effort to contact others involved in care, everything is carried out in own silos making service provision for the individual hard to follow or navigate. Too many hiding behind, unable to share information!"

"Lack of trust between clinicians and across sectors, leaving patients and families caught in the middle and unable to navigate or access the right care when they need it"

On funding

"Unlocking the commissioning and funding silos into a holistic and bundled payment model - matched with reporting to ensure accountability for delivery and learning"

"Salaries (not fee for service) for practitioners to free up their time so they can practice integrated care"

"Financial incentives and payment structures that `mandate` multidisplinary care in situ"

"A transformation of the payment system overcoming fragmentation between care providers so that objectives to be met and funding mechanisms are that of the territory and not of each of the individual providers"

"Incentivised through targeted use of contracts and performance improvement indicators that have as much weight as access and flow measures"

Are we there yet?

Conclusions and insights from the survey

No, we are not there yet!

The 2023 IFIC Survey got views across three different stakeholder groups on how they see continuity and coordination of care happening in their own settings. Service users, care providers and policymakers have responded that **continuity and coordination of care are already happening**. People see small and moderate advances, "signs of a new culture of integration" visible through experiments and local initiatives. **But we are not there yet: effective continuity and coordination of care is not yet fully established**.

In general, people have more positive views about achievements with care continuity over time than with coordination of care across multiple providers and settings. For example, 34.2% of the users agree with the view that the care they receive is continuous over time, which is not very high, but it is still higher than just the 26% of users believe that it is coordinated.

Service users have a more negative perception than providers of the degree to which care services are done with continuity and in a coordinated manner. Several service users noted how they keep telling their stories over and over again whenever they need help from the healthcare system and how continuity with the same health and care professionals is a challenge. The harsh message from service users is that **continuity and coordination ultimately fall on them:**

> "I am the person who co-ordinates my care. Appointments, blood tests, chasing referrals, PT, OT. It's up to me to decide and schedule everything.
>
> Only incidents are coordinated, like a surgery, and only within the limits that the hospital/surgeon control".

Health and care providers are committed to promoting care continuity and coordination. Despite recognising the shortcomings, they see improvements happening at the organisational level rather than at the system level. **There is a sense of optimism from policymakers and researchers,** widespread across the survey respondents from all over the globe, regarding advances in care continuity and coordination over the past years, although improvements are not consistent across the sectors or in countries, hence still much progress has to be made.

However, we seem to know what to do. We have at our disposal an **array of tools and interventions that can effectively promote continuity and coordination**, requiring addressing multiple actions and levers at the same time. The Survey asked views about advances along the following 8 mechanisms that facilitate both care continuity and care coordination:

1
Continuity with the same health and care professional over time

2
Coordinated joint planning of care and shared decision-making

3
Regular interdisciplinary teamwork including meetings

4
Co-located services in the same building

5
Technology to support continuity and care coordination

6
Specific care coordination roles

7
The availability of shared information/ shared care records

8
Direct involvement of patients and informal carers

While none of the 8 mechanisms is perceived as having gone very far, "Continuity with the same professional" and "Regular interdisciplinary team meetings" stand slightly above the rest. Advancements on the "Continuity with the same professional" mechanism are mostly noted by service users. This is essentially a mechanism of continuity of care, reinforcing the overall conclusion that more positive achievements are being seen regarding continuity than with coordination of care.

Promising news is that this slow-progress perception **is widespread across the survey participants all over the globe, from Nigeria to Canada to Singapore**. However, "changes are still embryonic", local and not consistent within and across countries. Hence, we are not there yet! There is still much progress to be made!

Appendix. Survey questions

Introduction

Welcome! Thank you for participating in this IFIC Survey 2023. The Survey seeks to get views across three different stakeholder groups on how they see continuity and coordination of care happening:

1. **What mechanisms/approaches/interventions make continuity and coordination of care possible?**
2. **Which mechanisms are considered most valuable (really effective) to promote care coordination and continuity?**

We will ask for your consent to participate in the survey. The survey is anonymous and your responses will only be used for this research and not shared with third parties. We do ask for some information about you to help us understand the pattern of responses we get, but it will not be possible to identify you from this. We will hold the responses to the survey securely in the Foundation's data repository and the data will only be used for the purpose of this research. If you have any further questions about the way IFIC will process your personal information or would like to exert your rights with respect to your data, please review IFIC's privacy policy at https://integratedcarefoundation.org/privacy-policy or contact info@integratedcarefoundation.org.

Completing the survey will take you less than 10 minutes. Thank you very much in advance!

Consent

Please, before continuing to the survey, be so kind to sign the consent form now, by selecting "Yes". Otherwise, please note that you will not be able to continue with the survey.

Q1. I am happy to continue with the questionnaire and understand that what I share here is confidential.

- ○ Yes
- ○ No

Information about you

Q2. Please, select your country below.

_____

Q3. What is your age?

- ○ Under 18
- ○ 18 - 29
- ○ 30 - 44
- ○ 45 - 59
- ○ 60-75
- ○ 75+
- ○ Prefer not to say

Q4. Gender: How do you identify?

- ○ Man
- ○ Non-binary
- ○ Woman
- ○ Prefer to self-describe, below
- ○ Prefer not to say
- ○ Self-describe: _____

Q5. In what capacity are you answering this questionnaire? You are a...
(Please, choose the one you identify with when responding to the survey).

- ○ User of health, care and support services
  (e.g., patient; citizen; unpaid carer; family; etc.)
- ○ Health and care provider (e.g., health and care professional; manager; paid carer; voluntary sector representative)
- ○ Policymaker or academic and/or researcher

Continuity of care

Q6. Thinking about the care services you receive or provide, to what extent do you agree that such care is continuous? [Continuity of care is the delivery of integrated care over time]

- ○ Strongly agree (All services are continuous over time)
- ○ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly disagree (No continuity at all)

Care coordination

Q7. Thinking about the care services you receive or provide, to what extent do you agree that such care is well coordinated? [Care coordination is the delivery of integrated care across multiple providers and settings]

- ○ Strongly agree (All services are continuous over time)
- ○ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly disagree (No continuity at all)

Continuity and coordination from a research and policy making perspective

Q8. Looking at a care service or system that you research or have policy making responsibility over, how far has it advanced in the provision of continuous and coordinated care in the last 5 years?

[Continuity of care is the delivery of integrated care over time and care coordination is the delivery of integrated care across multiple providers and settings]

- ○ Advanced significantly
- ○ Moderate advances
- ○ Small advances
- ○ No change
- ○ Actually got worse

Care coordination

Q9. Please, tell us why you answered to the previous question(s) as you did

Continuous and Coordinated care

Q10. For the integrated care movement, a number of mechanisms are suggested to be instrumental in the successful provision of continuous and coordinated care. Below you will find a list of some of these mechanisms and interventions. Please, score how advanced each one of them is in your own setting (the service that provides care to you; the service where you provide care; the system that you have policy responsibilities over; etc.)

	Very poor advancement in my setting	Poor advancement in my setting	Fair advancement in my setting	Good advancement in my setting	Very good advancement in my setting
Continuity with the same health and care professional over time					
Coordinated joint planning of care and shared decision-making					
Regular interdisciplinary teamwork including meetings					
Co-located services in the same building					
Technology to support continuity and care coordination					
Specific care coordination roles					
The availability of shared information/ shared care records					
Direct involvement of patients and informal carers					

Q11. What is the one thing that would make the most difference to coordination and continuity of care in your setting?

Thank you for taking the time to complete the survey!

Thank you for taking the time to complete the survey! We will be presenting the findings of the survey at the International Conference on Integrated Care ICIC23 in Antwerp (Flanders) in May 2023 and will publish a short report on our website at www.integratedcarefoundation.org