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Gathering data with soul

"Care Opinion is the most important person-centred care intervention we have done in the last decade…"

Professor Jason Leitch, Clinical Director, Healthcare Quality and Improvement, Scottish Government

This report explores the potential for the website Care Opinion to be used by members of the Specialist Cancer Charity Group (SCCG) to gather service user feedback and create communities in support of cancer care improvement.

It draws on the experience of people who use the online resource in different ways and I am very grateful for their insight, presented throughout the report in narrative form.

Their perspectives illustrate the power of Care Opinion to help bridge critical gaps – and all agree that the closer engagement of charities in using the website could prove a quality improvement gamechanger.

My thanks also go to the Care Opinion team – CEO James Munro, Head of Care Opinion Scotland Fraser Gilmore and Associate Director of Service Quality Sarah Ashurst – for all their help with the research.

Throughout the report I have added links to relevant web pages and research papers for further reference and attach a rage of pdfs to illustrate key points.

At the end I outline opportunities and further considerations for SCCG, and I look forward to following developments.

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About Care Opinion

In 2005 Sheffield GP Dr Paul Hodgkin launched an online feedback website to capture people's real-time experiences of receiving care, connecting them directly with their care providers to inform service improvement. Originally called Patient Opinion the site was renamed Care Opinion in 2017 and continues to develop its independent feedback gathering, moderation and dissemination role.

Care Opinion offers an easy-to-access online 'front door' for people to share their experience of health and care services, under a pseudonym and at a time of their choosing. Stories are carefully 'human-curated' by the Care Opinion team which moderates them according to principles[1] that ensure anonymity, clarity and accuracy before posting them on the public platform.

Seven core members of Care Opinion's team of 22 employees, based in Sheffield and Stirling, share moderation duties and all place strong emphasis on privacy and safeguarding both story-tellers and staff responders. The turnaround time between receiving the feedback and posting it to the site is typically 2-3 days.

Subscribing teams are alerted to messages relating to them as they are posted, and the resulting interaction between story-tellers and care providers takes place openly online. Graphics detail the number of times a story has been read and how long it takes to post a response, and any changes planned or made as a result of the feedback are clearly flagged.

There is a wealth of online and in-person training available to subscribing teams, who can analyse and present their data as they choose to develop services in partnership with the people that use them.

As staff confidence to engage on Care Opinion increases, so do story numbers. At the time of writing there were 617,400 postings on the site, with content building steadily as public awareness grows.

As the following case studies show there is nothing else like Care Opinion for immediacy of feedback. Where it is used well it is established as a trusted and non-partisan intermediary, linking anonymous story-tellers with care providers who want to learn from them directly. Stories on Care Opinion have been read more than 135.5 million times.

Care Opinion does not claim to be a one-stop shop for monitoring service user experience, but as a way of tracking it contemporaneously the platform fills a gap and complements

[1] https://www.careopinion.org.uk/info/moderation-principles#:~:text=To%20ensure%20the%20conversation%20is%20clear%2C%20we%20will%3A,CAPITALS)%20text%20with%20mixed%20case.

other feedback mechanisms including England's Friends and Family Test, the NHS website and online platforms for condition-specific patient communities such as HealthUnlocked[2].

Care Opinion is a not-for-profit Community Interest Company that generates income from 102 subscribing organisations, which include charities. In its financial accounts for the year to 31 March 2023, the CIC reported total net assets of £45,785[3].

Subscription options vary according to the level of support required, the size of the organisation and the number of staff responders there are. Individual contracts are negotiated directly and regarded as commercially confidential, but there is an indication of potential cost to develop a tailor-made service for SCCG in a proposal by Care Opinion CEO James Munro dated 14 December 2022 (*Attachment A*).

In England Care Opinion basic registration is available to all NHS Trusts allowing limited notification of local stories and offering a right to reply, which is used by most[4]. Some NHS organisations take out subscriptions and use Care Opinion to inform activity, but south of the border there is no national incentive.

In NHS Scotland a national Care Opinion subscription is paid for by the Scottish Government and provided to Health Boards free-of-charge. It is used widely across the acute sector (*see attachment B*) and there is contingency funding is available to extend it further. As National Clinical Director Professor Leitch says: "…we'd struggle to take it away now."

The functionality of the platform in Scotland is being developed in partnership between the Government, NHS users and Care Opinion and the learning is widely shared. Following Scotland's lead, in 2020 the Northern Ireland Public Health Agency also took out a national subscription making Care Opinion freely available in all five of the country's Health and Social Care Trusts, its Ambulance Trust, Blood Transfusion Service and Patient Client Council as well as the PHA.

In Northern Ireland, Care Opinion it is regarded as a priority. Despite the absence of a Stormont government the contract is being renewed annually and the PHA is also funding the cost of a part-time Care Opinion lead for each participating organisation to cascade learning.

Internationally, Care Opinion Australia operates on the same organisation-by-organisation basis as England, and there are plans for a similar Care Opinion Canada. Meanwhile there remains much work to do in the UK to extend the online feedback tool into primary care and social care, where the vast majority of patient interaction takes place and uptake of Care Opinion is low.

[2] https://healthunlocked.com/
[3] https://find-and-update.company-information.service.gov.uk/company/10824578
[4] https://www.careopinion.org.uk/listening

With honourable exceptions, General Practice does not yet participate in Care Opinion and few social care providers have yet engaged. But in Scotland 13 out of 31 Health and Social Care Partnerships (bodies responsible for adult social care, adult primary health care and unscheduled adult hospital care) are now subscribers to Care Opinion and using it to monitor experience across the piece.

As people tend to share experiences of their whole health journey, stories about community-based care are coming through anyway. Some professional and commercial cultures may be resistant to it right now, but growing reliance on digital technologies and increasing public expectation of online involvement in care improvement are expected to drive change.

Equity is a common concern when it comes to online access and Care Opinion offers a variety of ways for people to share their experiences – as well as keying it in, they can tell their story by freepost, with picture tiles or they can telephone for free and dictate it. Translation into British Sign Language and Irish Sign Language is provided by subscribers and work is ongoing to extend interpretation and translation options.

Some subscribers set up Care Opinion feedback 'kiosks' in clinical areas that do not require an author to log in to share key points, and others work face-to-face to support people to tell their stories using mobile technology. Analysis indicates that 83% of stories are submitted via the website, 11% through kiosks, 3% by leaflet and 2% by telephone (*see attachment C)*.

Limited demographic data (their role in the story, and whether they are an adult, young person or child) is collected when people post stories on Care Opinion, a deliberately light-touch approach to encourage participation. It is optional for authors to share their age, gender, ethnicity and disability, and around 10-15% choose to supply this. According to the Scottish data, 58% of authors are patients, 23% service users and 14% relatives; most are in their 60s, 58% are female and all are white (*see attachment C*).

Subscribers are also using Care Opinion to seek experiential feedback from communities whose voices are rarely heard. One study in the West of Scotland[5] was the first to investigate online feedback about palliative and end of life care, noting that novel insights were the appreciation of quality of care, staff professionalism, effective communication, and meeting patient's needs at end-of-life particularly by nursing staff.

Evidence is accumulating to demonstrate the impacts of online feedback, and advances in Artificial Intelligence will facilitate even more granular analysis of data in the future. It is described as a powerful tool for addressing the power imbalance that exists between large, impersonal health and care organisations and individuals who use their services. In Scotland, it is helping to humanise interactions, and positive stories are being used to counterbalance negative perceptions.

[5] https://journals.sagepub.com/doi/full/10.1177/23743735221103029

One research study into the experiences of lymphoma patients receiving care has suggested that people are surprised when they receive good NHS treatment, characterising themselves as 'lucky' [6] . Similarly, Care Opinion story authors say they are taken aback when they feel heard.

The story author

Sarah Sinclair* from Angus in central Scotland has spent the last year and a half helping her youngest son cope with acute lymphocytic leukaemia. Now aged 16, Tom* is midway through treatment at Dundee's Ninewells Hospital, and in general he enjoys good health and upbeat spirits. "He's remarkable – we are in and out of clinics all the time and he never complains," says Sarah. "So it breaks my heart when he has to go into hospital and it reduces him to tears."

Immunosuppressed by chemotherapy, Tom interacts with his large group of friends online. Admission to the paediatric unit at Ninewells, often for days at a time to treat sporadic infections, means no internet access, social isolation and plummeting spirits. "It has a real bearing on his resilience," says Sarah, who is by her son's side throughout. "I'd do anything to make him happy, which is why I posted on Care Opinion."

Having been told about the independent online feedback service by one of Tom's doctors, Sarah set aside her initial scepticism that anyone would bother to read it and composed a heartfelt message as statusbk45[7].

To her astonishment, she received a prompt reply. "I was totally shocked. At best I had expected an automated message saying 'thanks', but instead I made contact with a real person," she says. "If the changes that are being discussed do happen, I will 100% feel like I have achieved something thanks to Care Opinion."

There are now plans afoot to move the mirrors, fix broken blinds and re-decorate some inpatient rooms at Ninewells so they are more teen-friendly. Sadly, sorting out the IT issues that would keep Tom connected to the world as an inpatient remains an apparently intractable problem. "I'm going to keep at it though as it would make the world of difference to him," says Sarah. "It might sound like a small thing, but I am concerned that Tom would rather keep quiet about how he is feeling and avoid another admission with no way of accessing the internet. And that is potentially dangerous."

As a story author Sarah found Care Opinion easy to use and she welcomed the anonymity that allowed her to protect the identity of her son online. She also appreciates the potential for harnessing patient and carer experience to promote improvement. "You have nothing else to do but analyse the room you spend days in, and you spot things that need to be changed that others have missed - for instance, is it really a good idea to have coat hooks

[6] https://pubmed.ncbi.nlm.nih.gov/20579116/

[7] https://www.careopinion.org.uk/1128704

above the bins?" says Sarah. "It is good to know there are people listening who are prepared to make changes. I would certainly encourage others with experience to share to use Care Opinion."

**Names have been changed to protect the family's anonymity*

The Scottish experience

This report focuses on experience of using Care Opinion in Scotland, where in 2014 the Government entered a contract to provide full access to all NHS Health Boards – the first health system in the world to subscribe. 10 years on, the top-level commitment remains strong.

The NHS Scotland contract with Care Opinion for 2022-2026 is worth £800,000 over the four-year term, with a contingency to increase that by £100,000 for extension pilot programmes[8].

The national quality champion

The principal champion of Care Opinion in Scotland is Professor Jason Leitch, Clinical Director of Healthcare Quality and Improvement in the Scottish Government. Having introduced the acclaimed Scottish Patient Safety Programme[9] in the early 2000s, Jason went on to apply the same improvement methodology to person-centred care.

Initiatives such as 'Hello, my name is..' , 'What Matters to You', and open visiting were introduced across NHS Scotland, and after piloting and tendering Care Opinion was contracted to gather feedback from service users in 2014. Commissioned centrally, subscriptions are provided free of charge to all 14 territorial Health Boards and some national Boards including the Scottish Ambulance Service.

"I believe Care Opinion is the most important person-centred care intervention we have done in the last decade," says Professor Leitch. "It shines an independent light on the provision of health and care and the vast majority of the feedback is 100% positive. The way it works, by encouraging dialogue between service users and services, also helps to build trust."

From the beginning, the Care Opinion contract has received strong Ministerial support, and Members of the Scottish Parliament receive alerts to stories relevant to their constituencies. "It provides a very much more balanced view of what's happening in the health service than their regular inbox," says Professor Leitch. "The Health Minister and NHS Chief Executive both read postings regularly."

[8] https://www.publiccontractsscotland.gov.uk/search/show/search_view.aspx?ID=APR445037
[9] https://ihub.scot/improvement-programmes/scottish-patient-safety-programme-spsp/

Initially, there was resistance to the roll-out of Care Opinion within the Scottish health service. Staff feared that it would generate even more complaints, some referring to it disparagingly as 'Trip Advisor for healthcare'. But as experience of using it has grown, confidence has developed. "We never insisted that Boards take part, but have rolled it out by stealth," says Professor Leitch. "Like safety, we started small and took it from there. It's about building will."

To date, more than 40,000 Scottish stories have been posted on Care Opinion, 70% of them wholly positive. Around 20% of authors give mixed feedback and 10% are negative. "Communication issues are common, but there's the full continuum of experience reported," says Professor Leitch. "Sometimes stories expose problems that are easily sorted. Concerns about things like long waits and staffing levels are systemic problems and harder to fix, but they are noted."

Professor Leitch accepts that is difficult to prove the impact of Care Opinion. "The feedback that comes in may be softer than mortality or infection data, but we can still learn from it," he says. "We can scan trends by unit and service and flag any issues that need to be checked out. Similarly, more Health Boards are looking at their own Care Opinion data and using it to monitor performance."

Ultimately, it is a useful tool for shifting cultures. "Care Opinion is one way of getting rid of the 'nobody listens to me' complaint so often expressed by service users," says Professor Leitch. "And while health professionals are understandably nervous about receiving anonymised feedback, my advice is always to respond. We have seen the quality of responses improve as learning and skills develop, and confidence is building among frontline teams who are often best placed to reply."

For Professor Leitch, Care Opinion's unique selling point lies in its independence of the NHS, the ability to post stories anonymously, and the real-time insight it gives to what matters to people who use services. When it is fully mobilised across the acute sector, he would like to see Care Opinion adopted by Scotland's social care and primary care providers.

"Care Opinion is not expensive for the benefits it can bring and it is here to stay," says Professor Leitch. "Indeed, we'd struggle to take it away now."

To an extent, NHS Scotland's partnership with Care Opinion has been a leap of faith in the absence of much hard evidence of impact. However every report on critical incidents in the NHS in modern times has highlighted the vital contribution service user feedback can make to patient safety, and because of its immediacy it was felt there was logic in rolling Care Opinion out to complement other retrospective feedback-gathering exercises.

Research published in the Risk Analysis journal in 2022[10] validates that decision, concluding: "Online stakeholder feedback is akin to a safety valve; being independent and unconstrained it provides an outlet for reporting safety issues that may have been unnoticed or unresolved within formal channels."

[10] https://onlinelibrary.wiley.com/doi/10.1111/risa.14002

Another barrier is cultural. Described by US academic Brené Brown as 'data with soul', personal stories are by their nature qualitative and therefore difficult to interpret using conventional healthcare metrics. According to one systematic review of evidence on the links between patient experience and clinical safety and effectiveness[11]: "Clinicians should resist sidelining patient experience as too subjective or mood-oriented, divorced from the 'real' clinical work of measuring safety and effectiveness."

Shifting cultures takes time, but Care Opinion is now embedded within the Scottish Government Health Department where it is aligned to the national drive towards Realistic Medicine with its strong focus on patient-centred care.

The national learning lead

John Cameron, Senior Policy Manager in the Safety, Openness and Learning Unit in the Scottish Government, monitors Care Opinion's use across the health system, and senses a tipping-point. "Since it started, adoption has been a gradual process with local champions spreading the word," he says. "Having been light-touch in the past, we are now saying we expect all Boards to be fully subscribed to Care Opinion and using it. At the moment we are seeing an exponential rise in story numbers as the boards engage with, and embrace, the service."

There remain areas where Care Opinion is not being used (*see attachment B*). "There is still staff wariness to engage sometimes, and some of the smaller boards may have concerns about patient confidentiality in small populations," says John. "But there are Boards punching way above their weight given their size and we are learning from that."

Care Opinion is now an important part of the national improvement picture, complementing other feedback mechanisms but doing it differently. "It is becoming central to our overall approach. I'd like to think it's in with the bricks now," he says. "The feedback is qualitative so it is hard to measure impact but when we hear from staff using Care Opinion they regularly highlight the positive effects on morale and empowerment. I can see and feel the changes, and there's lots of bang for our buck."

For John, Care Opinion is "the only player in town" when it comes to giving people who use NHS services the opportunity to give feedback anonymously and in real-time via an independent intermediary, allowing transparent engagement with service providers.

Contracts awarded by the Scottish Government are subject to an open procurement exercise and no other provider has yet emerged to compete with Care Opinion. "It is difficult to prove that Care Opinion has diverted formal complaints, but it is certainly a good counter balance to the negative stories we see in the media" he says. "Staff feel appreciated, and it can be an early indicator of the need for change. For me, Care Opinion is one of the most positive things I have to deal with."

[11] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3549241/

The evidence base

Patients can be fearful of raising concerns in case it compromises their care[12], and many believe feedback to be futile: studies indicate that patient surveys are perceived as tick-box exercises and there is no expectation that the feedback will be read. A review by the National Institute for Heath and Care Research[13] reflects: "A lot of resource and energy goes in to collecting feedback data but less into analysing it in ways that can lead to change…."

People who use services also say they want to share their experience to improve things for others. The research paper Caring for Care[14], proposes that people who post their stories online are expressing their care for other patients, staff and the whole system when they share their experiences. Indeed, it concludes, conversations that take place online in themselves constitute an improvement in care.

Most patient and carer comments do not constitute complaints, and other than writing a 'thank you' card there are also few ways of expressing appreciation. Care Opinion offers anonymity to story authors, the vast majority of whom are extremely positive about their experience.

Unstructured self-reported feedback has been historically dismissed by health professionals, but it has the potential to disrupt what the authors of the paper Beyond Metrics?[15] describe as "taken-for-granted assumptions about quality, safety, and organizational performance to combat the complacency that can precede crisis."

Another paper examines implementing online feedback in a 'special measures' acute hospital to support an improvement journey[16]. It concludes: "The rapid implementation of online patient feedback can be achieved in a 'special measures' organisation. However, the difficulties of implementing such feedback should not be underestimated. In order to embed online feedback, staff members need to be engaged and feel supported, with opportunities to provide, respond and invite patient feedback frequently promoted to both patients and staff members."

In Scotland there is also recognised value in the system demonstrating a willingness to listen and learn, and humanising the interaction between large organisations and the individuals who use their services. Doing that well can come at a personal cost according to an ethnography of Care Opinion Scotland, Using humanity to change systems[17], by University of Aberdeen PhD student Emma Berry.

[12] https://www.england.nhs.uk/long-read/the-learn-from-patient-safety-events-lfpse-service/
[13] https://evidence.nihr.ac.uk/collection/improving-care-by-using-patient-feedback/
[14] https://www.sciencedirect.com/science/article/abs/pii/S0277953621006122?via%3Dihub
[15] https://www.sciencedirect.com/science/article/pii/S0277953615300435
[16] https://journals.sagepub.com/doi/full/10.1177/20552076211005962
[17] https://journals.sagepub.com/doi/10.1177/20552076211074489

To understand that better, Emma has looked at the support required for Care Opinion story authors, moderators and NHS staff, including emotional support. Further papers will explore differing treatments of positive and negative feedback stories, and senior leaders' perceptions of Care Opinion and its influence on organisational culture. Dr Berry has recently been awarded a PhD for her work and presents a poster on it on YouTube[18].

The academic researcher

Professor Louise Locock's academic interest in the potential for using patient experience to inform health care improvement predates Care Opinion, and she has followed the online feedback platform's development closely. "Scotland really is an international testbed for this approach," says Louise, Professor in Health Services Research at the University of Aberdeen. "Nowhere else has a centrally funded feedback model like this, and learning from it is rich."

So far, the majority of research relating to Care Opinion focuses on process[19] – looking at why and how it is used rather than assessing service-level change that results from it. Few outcomes are flagged by responders on the site itself, and there is sparse evidence that a rising number of online postings leads, for instance, to a reduction in formal complaints[20].

"Perhaps those are the wrong metrics," says Louise, who has published a paper exploring how staff use and respond to Care Opinion[21]. "It is generally accepted that narratives of care can be really powerful, but it is difficult for NHS staff to work out what to do with them. The culture they work in is numbers based, and narratives can be dismissed as flaky. But soft intelligence can also be informative."[22]

Instead of getting hung up on obvious measurables Louise supports the pursuit of more subtle transformation, likening it to an enlightenment model. "Some change comes from the accumulation of ideas and discussion, causing things to shift over time," she says. "In Scotland Care Opinion is being used for policy intelligence as well as improvement, helping teams to keep in touch with frontline perspectives. It is about hearing the patient voice and tackling the power imbalance.

"Some of it is about moral imperatives – the need to find a way of giving individual people a voice. We know that feedback can change attitudes if it is handled in the right way so it's more about cultural shift than single impact here."

The commitment to Care Opinion is very different south of the border, where there is no centrally funded government contract and it is up to individual Trusts to subscribe if they choose. Some use Care Opinion very well[23], responding to postings promptly and engaging authors, and others do it badly[24] by largely ignoring them. "The organisation and political

[18] https://www.youtube.com/watch?v=evOub1muRyk
[19] https://www.careopinion.org.uk/info/research-outputs
[20] https://www.careopinion.org.uk/blogposts/719/does-care-opinion-help-reduce-formal-complain
[21] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6978824/
[22] https://www.sciencedirect.com/science/article/pii/S0277953615300435
[23] https://www.careopinion.org.uk/opinions?nacs=rha
[24] https://www.careopinion.org.uk/services/rth

barriers are substantial in England where competition and market choice take priority," says Louise. "Scotland is following a very different route."

As she retires from her Chair, Professor Locock is preparing the join the board of directors for Care Opinion. "I look forward to continuing my interest in how we gather and apply service user feedback in healthcare," she says. "Because of its unique features Care Opinion has tons of potential to be a powerful lever for change."

There is anecdotal evidence of improvements that are made as a result of Care Opinion feedback locally, and the site itself records resulting changes, such as a ban on people wearing perfume in a neonatal unit[25]. So far there is no body of analysis of system-level impact, although the evidence base is growing.

Care Opinion has contributed to research studies at universities in London (LSE, Imperial College), Aberdeen, Bradford, Cardiff, Edinburgh, Leeds, Leicester, Nottingham, Oxford, Plymouth, Strathclyde and Sussex and hosts an active research community.

Work is now underway at Queen's University in Belfast to examine how Care Opinion data is used in practice, its use of AI, and whether it can be an early warning system for patient safety issues. At Leeds the research focus is on the use to which the feedback is being put, and at Nottingham there is further work underway on the impact of feedback on staff.

The national improvement advisor

Shaun Maher is Strategic Advisor in Healthcare Quality and Improvement at the Scottish Government and oversees Care Opinion's application across the system. "It's real-time, easy to use and bypasses the usual bureaucratic process," he says. "Not everything is worthy of making a formal complaint but it's still worth hearing, and how else can you capture positive experiences?"

A passionate advocate of person-centred care, Shaun has scanned the IT world for alternatives to Care Opinion for gathering feedback and found none. "Its unique characteristics include its independence of the system and that it is not-for-profit," he says. "There is high-quality moderation of postings and the team is very attentive to its responsibility to protect people. They take that extremely seriously and do a good job."

After moderation, perhaps to anonymise stories, identify potential legal issues or clarify points with authors, postings are put up on the Care Opinion website for all to see. "There is no fear or favour," says Shaun Maher. "If a story is particularly challenging it goes up nonetheless."

A departure from the usual feedback and complaints processes, Care Opinion's adoption by a traditionally defensive system was slow. "It took some Boards a few years to see that Care Opinion could be good for them, that their worst fears wouldn't manifest. It has been a slow

[25] https://www.careopinion.org.uk/508341

burn," says Shaun. "Now we are curating collaborative competition using the Care Opinion data and there are very few low users."

Shaun is aware that Care Opinion feedback does not provide a comprehensive picture of patient and carer experience as some parts of the service are enthusiastic promoters and users of the site and others are not. In addition few story authors volunteer demographic information. "There are blind spots and bright spots and we have to keep that in the forefront of our minds as we read the stories," he says. "But the more stories we gather the richer the picture is and the more revealing it can be."

Equity of access is a constant challenge, so Care Opinion facilitates feedback using the telephone, by post, with picture tiles, sign language interpretation and other forms of communication support. Beyond that, traditionally hard-to-reach groups can be targeted directly. "There have been stories collected in care homes, and good work done in palliative and end-of-life care[26]," says Shaun. "If you think creatively you can easily use Care Opinion in a specialist context."

Each NHS Board has a person-centred care lead, often the executive nurse director. At senior management level, Shaun would expect there to be regular reports on how feedback is being gathered, including use of Care Opinion, but impact is harder to capture as it is often not recorded.

"Care Opinion feedback matters most at the team level, helping frontline staff understand when they are doing a great job and indicating opportunities for improvement that they can act on," says Shaun. "The improvement happens there, while at the system level it can be difficult to detect."

Increasingly, it is frontline staff members – generally Charge Nurses – who respond to Care Opinion postings. "Where it works most effectively is where responsibility for responding is devolved," says Shaun. "People want to hear from the teams that provide their care, not some faceless corporate vacuum. How comfortable organisations are with that can be a good indicator of their own organisational culture."

Development of the Scottish platform and its application happens in partnership between Scottish Government data analysts, service-level users and Care Opinion. Together they are working to create innovative and informative ways to analyse the stories to illustrate national trends and highlight key themes, spotlighting feedback about individual services and running reports for wider dissemination (*see attachment D*). "At national level we are bringing lots of ability to explore new ways to understand these broader themes and issues raised by the public," says Shaun. "As we gather more feedback, the evidence becomes clearer."

Shaun observes that Boards which actively promote Care Opinion and generate stories typically enjoy a steady 75% to 80% positive story rating. By contrast, low-using Boards only

[26] https://journals.sagepub.com/doi/full/10.1177/23743735221103029

tend to hear from people who have more negative experiences and therefore look like they're performing more poorly. "So how do they know what they are doing well?" he says. "There's a natural competitive incentive to find out."

Recent research has explored the impact of positive feedback on care providers[27], and the potential for early identification of safety concerns[28]. "We are looking at how to ensure positive stories are being fed back to frontline teams so they know the impact they are making," says Shaun. "And if research shows that service users can be better at identifying safety concerns than staff working in the system, then let's make that easy for them. Care Opinion is not the solution, but it is an important source of intelligence if you use it properly.

For Shaun, the nature of the Care Opinion platform also humanises the interaction between the story author and service provider, leading to better communication. "It is a relationship-building platform, normalising person-to-person contact rather than a remote response," he says. "To me Care Opinion is one of the most impactful and important ways of demonstrating a culture of openness, bringing opportunities to learn and improve. In my opinion it is now a service-critical component of healthcare provider activities, a morale booster, improvement informer and safety valve."

Outcomes and impacts

Care Opinion merits no less than three namechecks in Scotland's National Cancer Strategy for 2023-2033[29]: *"Our aim is to ensure people with cancer are at the heart of service design. To achieve this, we will co-design whenever possible and we will regularly seek people's voices through direct feedback, for example through the Scottish Cancer Patient Experience Survey and Care Opinion."*

As a result of feedback received, the Cancer Strategy's underpinning Recovery Plan for 2023-2026[30] includes an ambition to provide all cancer patients with a single point of contact and 12 pilot projects are underway to explore how to achieve that.

The national cancer care advisor

Debbie Provan, Clinical Advisor in the Scottish Government's Cancer and Rehabilitation Unit, and her team have been closely following the national Care Opinion feedback since early 2021. Together they read every story related to cancer care north of the border. She is in no doubt that it has impact.

[27] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0275045
[28] https://onlinelibrary.wiley.com/doi/10.1111/risa.14002
[29] https://www.gov.scot/publications/cancer-strategy-scotland-2023-2033/#:~:text=This%20Cancer%20strategy%20for%20Scotland,experience%20and%20our%20wider%20partners.
[30] https://www.gov.scot/publications/cancer-action-plan-scotland-2023-2026/pages/3/

"Stories generally echo the findings of the Scottish Cancer Patient Experience Survey in that 95% of experience is positive. However, we know there are improvements to be made such as communications between primary and secondary care to reduce uncertainty for patients," she says. "That was really visible through Care Opinion, and it was a wicked problem we wanted to address."

A link worker for every cancer patient In Scotland and the Single Point of Contact Initiative Is the response. "Care Opinion is not a panacaea but it works as well as, if not better than, other ways of gathering lived experience," says Debbie. "It all depends on how we use it."

To systematise the process of gathering stories that illustrate what is and what is not working for people who use cancer services, a Framework for Change is being developed by Debbie's team. It sets out how experience is gathered and used by policy makers and explores ways in which they can improve and learn from lived experience.

At national level, Debbie and her team use Care Opinion by running reports on over-arching themes in specific service areas and drilling down into priorities such as earlier diagnosis and communication. "The cancer journey spans primary care and acute and although GP practices are not routinely using Care Opinion, we still get to hear about that," she says. "We then raise any issues through the relevant existing forums so that primary care colleagues are aware and themes can be addressed."

For Debbie, Care Opinion's immediacy is its big advantage. "Although really valuable, the Cancer Experience Survey happens once every few years, there's a 60% response rate and a timelag before it reports," she says. "Care Opinion allows us to learn from those affected by cancer, their carers and families, as they are going through it."

Wider promotion of Care Opinion is necessary to improve public awareness of the site and therefore boost story numbers, so Debbie and her team encourage partners such as the Third Sector and the Scottish Cancer Coalition, made up of 32 cancer charities, to spread the word. "There are about 33,000 cancer diagnoses each year in Scotland, and maybe 50 Care Opinion postings about cancer each month," she says. "Story numbers are rising as more Boards come on, but if charities were to engage their populations and encourage postings it could boost participation considerably and help to change the game."

Greater numbers of stories would improve the diversity of those sharing their feedback, but it could also impose stresses on the system to respond promptly and act on what they learn. "Devolving responsibility for responding to frontline teams spreads the load, and training and support can help staff develop their confidence with Care Opinion.," says Debbie. "There is no obvious viable alternative to Care Opinion. Staff and teams should not be fearful of feedback, and although it is sometimes challenging and upsetting it is also very rewarding to receive appreciation and learn directly from the people receiving cancer care. We want that to be part of the culture."

The frontline view

Scotland's 14 territorial NHS Boards all have full access to Care Opinion and staff on the frontline are using it widely (*see attachment E*).

The local Care Opinion lead

NHS Tayside is currently a Care Opinion super-performer. Having notched up a grand total of 870 postings over the first five years of its subscription, story numbers suddenly took off with the appointment of Victoria Sullivan as the Board's Care Opinion lead in October 2021. "We're up to 2,741 stories now and the number is doubling each year," she says. "90% of our services are using Care Opinion to gather feedback from their patients, and 85% of that is positive. It hasn't reduced complaints, but it has increased the compliments."

When she was tasked with revitalising NHS Tayside's use of its free subscription to Care Opinion, former admin manager Victoria discovered a passion for service user feedback and set about transforming the way Care Opinion is used across the organisation. She spread the word to staff through newsletters (*see attachment F*), on hospital radio and through in-person briefings and offered support to teams who were interested in trying it out, maximising all the online and in-person training on offer.

Promotional materials and leaflets were distributed, QR codes were created to take story tellers straight to the relevant section of the Care Opinion website, and as feedback started coming in staff engagement took off.

Now the Board ranks No. 2 in the UK for its number of Care Opinion responders – 681 of at the time of writing, mainly nurses – and there is evidence of impact. For instance, as the result of one story where the author expressed surprise that, unlike in fixed locations, there was no warning about the noise in mobile MRI scanner units, advisory notices went up.

"Around 70 of our stories have so far resulted in documented changes but there's a lot of benefit that goes unreported," says Victoria. "Care Opinion feedback is typically positive and people can name members of staff they are saying 'thanks' to, which can be used to support medical and nursing revalidation. Evidence is really powerful when it's in the patient's voice."

Victoria, who also project manages the NHS Tayside diabetes pathway, works on Care Opinion one day a week and takes personal responsibility for ensuring that postings reach the right people. "A story might mention the catering, a porter, the anaesthetist, the parking – I make sure all the messages are passed on," she says. "People feel better when they know they've done a good job, and problems are reported to the right place."

NHS Tayside's enthusiastic take-up of Care Opinion has been noted nationally, and the team was recently invited to present at a Realistic Medicine conference. The NHS Tayside Board also takes a close interest in progress and receives regular reports. "I would like to see patient feedback taken as seriously as complaints by the system," she says. "We can learn as much from what is being done right as what goes wrong. Demonstrating that is important."

Victoria finds that Care Opinion data can be easily analysed and presented in different ways[31]. "You can cut the information any way you want, and visualise it how you like," she says. "Our responders are using it on the ground and making it their own."

Care Opinion support includes online and offline training for staff who respond to postings and encourage feedback. "The Care Opinion team will come to us to do bespoke training if required, and we do use them a lot," says Victoria. "They have been very responsive and we are working together to roll it out."

The platform is now promoted across NHS Tayside, including the region's two acute hospitals, Perth Royal Infirmary and Dundee's Ninewells. Volunteers with mobile computers have been gathering feedback from people using chemotherapy and radiotherapy services to great effect, and further such initiatives have started in renal and maternity. "When you work on it, story numbers skyrocket," says Victoria. "People are really pleased to tell us what they think."

As Care Opinion authors share stories that span the care spectrum, Victoria is encouraging the wider system to subscribe to Care Opinion and learn from their experience. "We are building a picture of the whole patient journey from what people are telling us anyway and we pass those messages on," says Victoria. "There is a natural fear of negative feedback and there can be resistance, but people are usually pleasantly surprised when the stories start coming in."

The three Tayside Health and Social Care Partnerships (Dundee City, Perth & Kinross and Angus) are now fully signed up to Care Opinion and using the site to gather feedback about community services. "It's a question of equity," says Victoria. "Everyone should have access to feedback, and everybody should be using it to improve."

Concerns about inequity of access for people giving feedback via Care Opinion are misplaced, according to Victoria. Instead, she believes the site offers innovative ways of hearing from traditionally unreached groups.

Stories can be submitted in a variety of ways and can be translated into British and Irish Sign Language on the website. NHS Tayside is also working with Care Opinion to extend the translation and interpretation options on offer to include foreign languages. "We want to make it as easy as possible for people to tell us what they think and to understand our response," says Victoria. "Care Opinion allows us to target particular groups – maybe men, people from ethnic minorities or the elderly – and gather their stories in their own words in the here and now."

Looking to the future, Victoria hopes that the Scottish Government's sponsorship of Care Opinion continues. "It would take an awful lot of work to replicate the wealth of data that we are gathering now," she says. "There is lots more to do, loads of patient groups still to

[31] https://www.careopinionstoryboard.dx.am/tafjufm339je.html#all-stories

hear from. I'd like to keep pushing Care Opinion out further to encourage even more stories that we can learn from to improve."

Thanks to dedicated local leadership, NHS Tayside offers support to any team that wishes to gather feedback about its services. In some clinical areas trained volunteers visit regularly to encourage the sharing of patient and carer experience.

The feedback volunteer

Far from being reluctant to use online technology, NHS Tayside volunteer Donna Fraser finds that the vast majority of patients and carers she speaks to about Care Opinion are digitally literate and willing to try it out. "Even older people have mobiles with all the latest tech, and most use texts and email routinely," she says. "People show me photos on their phone all the time and when I suggest they share their experiences online they're typically happy to give it a go."

Equipped with leaflets and a tablet computer (when a working one is available), Donna spends one day a week in the Ninewells Hospital chemotherapy outpatients department, sharing information about Care Opinion and inviting feedback. "Most of the patients haven't heard of it before, and they are genuinely happy with the experience they receive so don't want to complain," she says. "I explain that positive feedback matters too and nudge them to give it a go."

Care Opinion feedback is welcomed by the care team and stories receive responses directly from the Senior Charge Nurse. The website is promoted throughout the department and posters carrying QR codes are prominently displayed.

A retired psychiatric nurse, Donna was herself treated for cancer at Ninewells during the height of the Covid pandemic. "I can't fault these guys and I decided to volunteer because I wanted to give something back," she says. "The nursing assistants don't have the time to spend with people, just chatting and encouraging them to share what they think. Volunteers with the right skills can do that. You've got to be able to read people, something I learned from my 30 years of clinical practice. This is a great role for me."

Since she started her Care Opinion awareness drive, Donna has seen the number of stories about the department soar. "The majority is people saying 'thanks' and praising the service, and I know how much that is appreciated - if someone tells you you've done a great job you feel like all the hard work is worthwhile," says Donna. "But feedback can also flag up problems. Whether it's lack of parking, or the quality of the coffee, I tell people it's important to hear about it. Experience matters or you're not going to want to come back."

Cancer charity perspective

As Care Opinion seems set to be an integral part of Scotland's NHS ecosystem for the foreseeable future there is growing interest among Third Sector organisations to follow its findings. Anyone can access the website to monitor postings and responses, but greater insight comes with registration and formal subscription to the service and some charities have been considering that.

The cancer charity Lead

Janice Preston, National Lead for Macmillan Cancer Support in Scotland and Northern Ireland, sees enormous potential in Care Opinion. When the platform was first introduced, Macmillan was working with NHS Lanarkshire, an early adopter, to implement the charity's Values Based Standards (VBS). A method for understanding and measuring patient experience, VBS brought together clinicians and people who use services to prioritise developments, and Care Opinion feedback helped to shape resulting improvements.

"Whenever there are big critical incidents or behaviours affecting care delivery such as Mid-Staffordshire I think 'if only we could see the warning bells'," she says. "Care Opinion feels like a great vehicle for gathering patient and carer experience to pick up problems early and inform improvement."

A chemotherapy nurse by background, Janice has witnessed how Care Opinion is being used across cancer services in Scotland and as the volume of feedback grows so does the learning. Macmillan already has teams on the ground capturing insights to inform the charity's work, and Janice can see how greater use of Care Opinion would complement that. "Care Opinion offers a tried-and-tested way to gather real time feedback," she says. "Why reinvent the wheel?"

The data used for improving care, including the results of the Cancer Care Experience Survey, is typically retrospective and out-of-date by the time it is released. "The beauty of Care Opinion is that it is in-the-moment, independent of care providers, and totally transparent," says Janice. "And nowhere else captures good feedback as well as bad. We could be tracking experience as it is happening, picking up risky cases a lot quicker and focusing in on current themes."

Macmillan UK has been considering working in formal partnership with Care Opinion for some time. One option, for a small fee, is to contract Care Opinion to provide regional reports to inform Macmillan's work on the ground; another is to subscribe to the platform fully in order to gather feedback from people who use Macmillan's own services. "I am keen that as a charity we see what Care Opinion might hold for us," says Janice. "It would undoubtedly be a useful improvement tool, but we haven't explored it in detail yet."

The charity's contribution to the partnership would be increasing awareness of Care Opinion in communities. Macmillan had started developing volunteer profiles for people to promote the platform on the ground when Covid struck and progress stalled. "We recognise that we have a wealth of contacts that we can use to boost awareness," says Janice. "People trust charities and if we asked them to share their stories to help services to improve, I am sure they would."

Janice sees potential for cancer charities to work together, perhaps negotiating a collective Care Opinion subscription and sharing the cost and administrative overhead of ensuring that data is gathered, analysed and shared. “Joining forces in this way makes sense,” she says. “As well as learning about our own performance, we could be sharing links to relevant charity services, using the data to campaign for better care, showcasing where things are working well and proactively spreading good practice.”

Analysis of large amounts of anonymous data is a powerful agent for improving services and in Scotland Janice believes there are opportunities for integrating Care Opinion through the national programme Improving the Cancer Journey[32] (ICJ). A partnership between the Scottish Government and Macmillan Cancer Support, ICJ looks to ensure that everyone affected by cancer in Scotland has access to a key support worker who can co-ordinate holistic needs assessment, usually electronically, and act as a patient’s single point of contact with the system. It is a key ambition in the National Cancer Strategy.

“These key workers could be pivotal to support feedback about experiences across the whole care spectrum, reaching people who are traditionally disenfranchised including people with language or literacy issues and those living in the most deprived communities,” says Janice. “It is possible to make a national approach happen here in Scotland - in the rest of the UK it takes longer and there are different priorities, but this is definitely the direction of travel as the outcomes we are seeing are difficult to ignore.”

Overcoming the resistance of social care and primary care providers, who fear that Care Opinion would simply attract criticism and complaints, is required. “But people are posting numbers of stories about their whole care journey anyway, so why not listen to them?” says Janice. “If the cancer charities were to promote Care Opinion the number of stories could grow dramatically and the data would be richer. It could be a very powerful tool to lever pan-system change.”

Opportunities and considerations

Care Opinion represents a powerful tool for realising the vision of the SCCG to ‘create an engaged patient and clinical community that acts as a catalyst for change’. Indeed, fostering human connection seems to be its USP and there is no other online vehicle that offers the same service.

There is strong agreement among the people I have spoken to in preparation of this report that the closer engagement of specialist cancer charities, either individually or collectively, in Care Opinion would add significant value to the quality-improvement feedback drive.

A key consideration for SCCG is what purpose subscription would serve – is the desire to gather contemporaneous feedback about charity services that are delivered directly, to focus on people’s experiences of receiving cancer care more generally in order to glean local and

[32] https://www.gov.scot/news/further-investment-in-cancer-support-services/

national intelligence to influence change, to signpost authors to information and support, or perhaps to harness positive stories for morale-building and to foster healthy cultures?

Depending on the objectives, there is potential for SCCG members to take a single subscription and co-ordinate Care Opinion activity as a group. Lead role functions could revolve, spreading the load of monitoring stories, responding to them and disseminating them to subscribing partners.

The resources required will be determined by the scale of the task, but time commitment is not likely to be onerous. In Northern Ireland the Public health Agency has committed funding for a staff member to work two days a week on Care Opinion in each subscribing Trust; the person leading it in NHS Tayside achieves a great deal in one day a week. SCCG members could share that overhead between them.

There appears to be no advantage in having a separate 'cancer hub' on Care Opinion, which is currently showing no activity online. It is an advantage for those giving feedback that there is one front door to access the platform, where people tell stories that they may not directly relate to cancer care and which may span systems and providers. Instead, the keyword function can be easily used to collate self-reported experience by multi-layered themes. It is more about creating communities of staff than communities of patients.

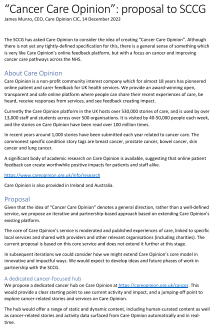
Full subscription would allow the participating charities to follow relevant postings, respond to them as appropriate, and drill into data according to their needs. Extensive training and support is provided by the Care Opinion team which works alongside subscribers to develop the service.

With training, charity volunteers would also be well-placed to work in communities where people receive cancer care to support them to share their stories online. By, for instance, making computers available in easy-to-access locations and supporting people to use them, charities could also promote equality and help to ensure that people who rarely share their views are heard.

If charities were to exercise their collective might by systematically spreading the word about the potential power of Care Opinion feedback, story numbers would surely increase. Partnering with Care Opinion to promote the feedback service and significantly enrich the dataset is a strong starting position for negotiating what could be a landmark and dynamic subscription.

Pennie Taylor

Attachments



"Cancer Care Opinion": proposal to SCCG

James Munro, CEO, Care Opinion CIC, 14 December 2022

The SCCG has asked Care Opinion to consider the idea of creating "Cancer Care Opinion". Although there is not yet any tightly-defined specification for this, there is a general sense of something which is very like Care Opinion's online feedback platform, but with a focus on cancer and improving cancer care pathways across the NHS.

About Care Opinion

Care Opinion is a non-profit community interest company which for almost 18 years has pioneered online patient and carer feedback for UK health services. We provide an award-winning open, transparent and safe online platform where people can share their recent experiences of care, be heard, receive responses from services, and see feedback creating impact.

Currently, the Care Opinion platform in the UK hosts over 530,000 stories of care, and is used by over 18,000 staff and students across over 500 organisations. It is visited by 68-90,000 people each week, and the stories on Care Opinion have been read over 180 million times.

In recent years around 1,000 stories have been submitted each year related to cancer care. The commonest specific condition story tags are breast cancer, prostate cancer, bowel cancer, skin cancer and lung cancer.

A significant body of academic research on Care Opinion is available, suggesting that online patient feedback can create worthwhile positive impacts for patients and staff alike.

https://www.careopinion.org.uk/4/research

Care Opinion is also provided in Ireland and Australia.

Proposal

Given that the idea of "Cancer Care Opinion" denotes a general direction, rather than a well-defined service, we propose an iterative and partnership-based approach based on extending Care Opinion's existing platform.

The core of Care Opinion's service is moderated and published experiences of care, linked to specific local services and shared with providers and other relevant organisations (including charities). The current proposal is based on this core service and does not extend it further at this stage.

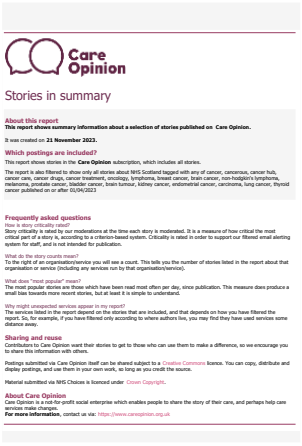
In subsequent iterations we could consider how we might extend Care Opinion's core model in innovative and impactful ways. We would expect to develop ideas and future phases of work in partnership with the SCCG.

A dedicated cancer-focused hub

We propose a dedicated cancer hub on Care Opinion at https://cancer.careopinion.org.uk/cancer. This would provide a clear starting point to see current activity and impact, and a jumping-off point to explore cancer-related stories and services on Care Opinion.

The hub would offer a range of static and dynamic content, including human-curated content as well as cancer-related stories and activity data surfaced from Care Opinion automatically and in real-time.

A –Cancer Care Opinion proposal December 2022



Care Opinion

Stories in summary

About this report

This report shows summary information about a selection of stories published on Care Opinion.

It was created on 21 November 2023.

Which postings are included?

This report shows stories in the Care Opinion subscription, which includes all stories.

The report is also filtered to show only all stories about NHS Scotland tagged with any of cancer, cancerous, cancer hub, cancer care, cancer drugs, cancer treatment, oncology, lymphoma, breast cancer, brain cancer, non-hodgkin's lymphoma, melanoma, prostate cancer, bladder cancer, brain tumour, kidney cancer, endometrial cancer, carcinoma, lung cancer, thyroid cancer published on or after 01/04/2023

Frequently asked questions

How is story criticality rated?

Story criticality is rated by our moderators at the time each story is moderated. It is a measure of how critical the most critical part of a story is, according to a criterion-based system. Criticality is rated in order to support our filtered email alerting system for staff, and is not intended for publication.

What do the story counts mean?

To the right of an organisation/service you will see a count. This tells you the number of stories listed in the report about that organisation or service (including any services run by that organisation/service).

What does "most popular" mean?

The most popular stories are those which have been read most often per day, since publication. This measure does produce a small bias towards more recent stories, but at least it is simple to understand.

Why might unexpected services appear in my report?

The services listed in the report depend on the stories that are included, and that depends on how you have filtered the report. So, for example, if you have filtered only according to where authors live, you may find they have used services some distance away.

Sharing and reuse

Contributors to Care Opinion want their stories to get to those who can use them to make a difference, so we encourage you to share this information with others.

Postings submitted via Care Opinion itself can be shared subject to a Creative Commons licence. You can copy, distribute and display postings, and use them in your own work, so long as you credit the source.

Material submitted via NHS Choices is licenced under Crown Copyright.

About Care Opinion

Care Opinion is a not-for-profit social enterprise which enables people to share the story of their care, and perhaps help care services make changes.

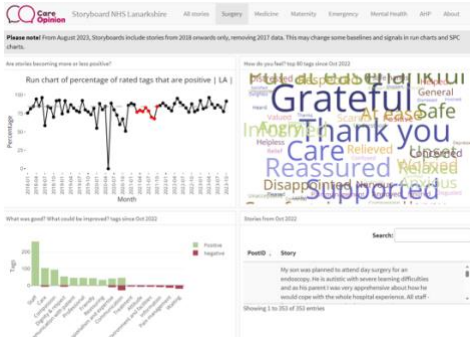
For more information, contact us via: https://www.careopinion.org.uk

B – Stories in summary (Scotland)

Care Opinion

Story authors in summary

C – Care Opinion story authors in summary (Scotland)



D – Feedback storyboard

Responses and story progress

E – Care Opinion responses and story progress (Scotland)

Care Opinion Newsletter
September 2023

Welcome to our newsletter for September 2023 which features our new look! A very special welcome also to Tayside's newest Care Opinion services, including Children's Continence Services, Orthotics, General Surgery and Surgical Acute Frailty Teams, Oncology Specialist Nurse teams, the Clinical Research Imaging facility, Surgical Outpatients in Ninewells Hospital, Angus Outpatient departments and the Diabetic Dietitians.

Autumn Events Programme

Care Opinion Newsletter September 2023 Page 1

F – NHS Tayside Care Opinion newsletter

ENDS