Improving Cancer Services

Patient Feedback and Experience Intelligence Programme

Transforming Patient Voice into Actionable Intelligence

Draft Strategic Discussion Paper | Version 2.0

For Stakeholder Review and Contribution

Programme Overview

The Patient Feedback and Experience Intelligence Programme is designed to help NHS cancer organisations unlock the full potential of the patient feedback they already collect. Every Trust, Cancer Alliance and Integrated Care Board receives patient feedback in multiple forms — structured survey responses, open narrative comments, CareOpinion posts, patient forum discussions, post-treatment questionnaires. This programme provides the analytical framework, the technology infrastructure and the strategic methodology to transform that feedback from information collected into intelligence acted upon.

At the heart of the programme is a single, organising insight: the Cancer Quality of Life Survey (CQOLS) tells us what patients are experiencing — the measurable dimensions of health-related quality of life, the scale of burden, the gap between how patients are and how they could be. Patient narrative feedback explains why they are experiencing it — the specific service failures, communication breakdowns, support deficits and care coordination problems that drive the patterns CQOLS captures. Neither source is sufficient alone. Together, they create an intelligence picture of unusual depth and precision: one that identifies not only where quality of life is poorest but why, and therefore what organisations need to do to improve it.

The programme brings together three evidence streams. The first is the SIA EQ-5D Plus structured outcomes instrument, which combines the internationally validated EQ-5D and EORTC QLQ-C30 quality of life measures with three open patient-narrative questions, creating a single data collection instrument that generates both quantitative outcomes data and qualitative patient experience evidence. The second is CareOpinion, the national patient narrative platform, whose data can be systematically analysed using AI-driven text analytics to identify themes, sentiment and areas of highest concern at scale. The third is CQOLS itself, which provides the benchmarked, validated population-level quality of life intelligence against which local patient feedback can be contextualised and interpreted.

This paper sets out the programme in full — its rationale, its methodology, its evidence base and the opportunities it creates for NHS organisations at every level to use patient intelligence more powerfully and more systematically than has previously been possible.

Executive Summary

The Untapped Value of Patient Feedback

The NHS collects an extraordinary volume of cancer patient feedback. Across Trusts, Cancer Alliances and ICBs, tens of thousands of patients each year share their experiences of cancer care through surveys, questionnaires, narrative comments and online platforms. Much of this feedback reflects real and significant experiences: fear and uncertainty during the diagnostic journey; distress at the side effects of treatment; a sense of abandonment when active treatment ends; unmet needs for information, emotional support and practical help in the months and years that follow. It represents an invaluable window into the lived reality of cancer care — and it is, to a very considerable degree, underused.

The challenge is not primarily one of volume. The problem is that patient feedback, in its raw form, is difficult to analyse systematically and at scale. Open narrative comments are time-consuming to read and categorise manually. Survey responses produce numbers without context. When organisations do analyse their feedback, they typically do so locally, retrospectively and without the methodological consistency that would allow meaningful comparison across sites or time periods. The result is that the intelligence latent within patient feedback — the signals about where care is falling short, where communication is breaking down and where patients are being left without the support they need — remains largely unrealised.

What This Programme Delivers

The Patient Feedback and Experience Intelligence Programme addresses this challenge directly. By combining AI-driven text analytics with validated quality of life instruments and CQOLS benchmarking, it creates a systematic, scalable and consistently applied methodology for extracting intelligence from patient feedback and linking it to the measurable outcomes that CQOLS captures. The programme does not replace existing feedback mechanisms; it enhances them, adding the analytical capacity and the interpretive framework to make the intelligence they contain actionable.

At the level of individual Trusts, the programme enables organisations to identify the themes that matter most to their patients, to track sentiment over time, to detect emerging areas of concern before they become entrenched problems and to understand the relationship between the service experiences patients report and the quality of life outcomes CQOLS measures. At Cancer Alliance and ICB level, it enables system-level intelligence — identifying patterns that transcend individual sites, supporting benchmarking, informing commissioning and providing the evidence base for strategic service redesign.

The Evidence Already Available

The intelligence potential of this approach is not theoretical. Analysis of existing patient feedback data — from national CareOpinion data, from patient forum discussions and from

structured open-question responses — has already identified clear, consistent and clinically significant signals. Patients describe a pervasive sense of abandonment when active treatment ends, characterised by inadequate follow-up, poor information about what to expect and a feeling that the system which mobilised so effectively around their diagnosis and treatment has suddenly disengaged. They describe communication failures at every stage of the pathway — delays in receiving information, inconsistent messages from different clinical staff, inadequate explanation of treatment options and their consequences. They identify specific operational concerns around timeliness and responsiveness that go beyond the waiting time targets the NHS routinely measures.

These signals are not random or isolated. They cluster in ways that correspond directly to the quality of life dimensions that CQOLS measures. When CQOLS identifies that patients in a particular service are reporting higher levels of emotional distress, analysed patient feedback explains why: the emotional support deficit that patients themselves describe. When CQOLS identifies mobility and functional limitations, patient feedback reveals the rehabilitation and self-management support that patients are not receiving. The two sources of intelligence, read together, create a diagnostic picture that neither could produce alone.

The Opportunity

The opportunity before NHS cancer organisations is significant and achievable. The data required already exists. The analytical technology is proven and deployable. The methodological framework this programme provides makes the connections between feedback and outcomes explicit and systematic. What is required is the organisational commitment to treat patient voice not as a compliance obligation but as a strategic intelligence asset — to close the loop between what patients tell us and what we do in response, and to build the culture and infrastructure of a learning system that continuously improves care based on evidence drawn from those who receive it.

Chapter 1
The Case for Patient Feedback Intelligence

Patient Feedback as a Strategic Asset

Patient feedback occupies an unusual position in the NHS. It is valued in principle — as a marker of compassionate, person-centred care, as a legal requirement under the Patient and Public Involvement framework, and as a formal source of evidence for inspection and regulatory purposes. Yet in practice, the gap between the feedback that is collected and the intelligence that is acted upon remains wide. The NHS gathers vast quantities of patient experience data, and much of it either never reaches the people who could act on it, or reaches them too slowly, in too fragmented a form and without the analytical framing that would make its meaning clear.

This gap carries real costs. When patient feedback remains unanalysed or underanalysed, the opportunities it represents for service improvement are missed. Problems that patients have clearly identified — a communication failure in post-treatment follow-up, an operational bottleneck in diagnostic pathways, a deficit in emotional support provision — persist and compound. Patients continue to experience them. Quality of life continues to suffer. And the NHS forgoes the learning it needs to improve. The case for a more systematic, more analytical and more strategically ambitious approach to patient feedback is, in this sense, simultaneously a case for better patient outcomes and better use of public resources.

From Feedback to Intelligence: The Analytical Shift

The distinction between feedback and intelligence is important. Feedback, in its raw form, is information that patients provide about their experiences. Intelligence is what that information becomes when it is systematically collected, analytically processed, contextualised against other evidence and transformed into a basis for organisational learning and action. The shift from the former to the latter requires three things that have historically been difficult to achieve at scale: analytical consistency, interpretive framework and organisational follow-through.

Analytical consistency means that feedback is collected, categorised and analysed using methods that are applied reliably across time, across sites and across patient groups — so that patterns can be identified, trends can be tracked and comparisons can be made. Interpretive framework means that the analysis is conducted within a conceptual structure that connects what patients report to the clinical and operational dimensions that matter — so that feedback does not remain an account of experience but becomes evidence about the specific aspects of care that need to change. Organisational follow-through means that the intelligence that emerges from analysis is communicated to the people who can act on it, in a form that

enables them to act, and that the system tracks whether action has been taken and whether it has made a difference.

The CQOLS Connection: What and Why

The National Cancer Quality of Life Survey provides the 'what' of cancer patient experience at population scale. It is a validated, nationally consistent instrument that captures health-related quality of life across five domains — mobility, self-care, usual activities, pain and discomfort, and anxiety and depression — alongside a Visual Analogue Scale for overall health assessment and the broader multidimensional quality of life profile captured by the EORTC QLQ-C30. Its value lies in the fact that it is systematic, comparable and clinically grounded: it tells organisations precisely how their patients are doing relative to national benchmarks, and in which quality of life dimensions the greatest burden lies.

What CQOLS cannot provide, by its nature, is the explanatory 'why': the specific service experiences, care pathway failures and support deficits that produce the quality of life patterns it measures. For this, patient narrative is indispensable. When CQOLS identifies elevated anxiety among post-treatment patients at a particular Trust, it cannot by itself explain whether this reflects inadequate follow-up communication, insufficient access to psychological support, unresolved concerns about recurrence risk, or some combination of these. Patient feedback can. The two sources, read together, are considerably more powerful than either alone — and the programme described in this paper is specifically designed to bring them into productive relationship.

The Scale of the Opportunity

The opportunity this approach represents is not incremental. Across the NHS cancer system, there are currently hundreds of thousands of patients each year sharing experiences that contain detailed, clinically significant intelligence about the gaps in the care they receive. With the analytical infrastructure this programme provides, that intelligence becomes systematically accessible — not just to individual clinical teams reviewing individual comments, but to Cancer Alliances and ICBs with the strategic remit to identify patterns, set priorities and drive system-level improvement. The transition from a model where patient feedback is a compliance activity to one where it is a core intelligence function has the potential to fundamentally change how NHS cancer organisations understand and respond to the needs of the people they serve.

Chapter 2
The SIA EQ-5D Plus Methodology

Combining Structured Outcomes with Patient Narrative

The SIA EQ-5D Plus instrument is the primary data collection tool of the Patient Feedback and Experience Intelligence Programme. It is designed to address a fundamental limitation of conventional patient experience surveys: the separation between structured, quantitative outcomes measurement and open, qualitative patient narrative. Most surveys do one or the other — they either collect validated quality of life scores or they invite patients to share their experiences in their own words. The SIA EQ-5D Plus does both, within a single instrument, creating a dataset that is both analytically rigorous and humanly rich.

The structured component of the instrument comprises the internationally validated EQ-5D quality of life questionnaire and the EORTC QLQ-C30 cancer-specific outcomes measure. The EQ-5D captures health-related quality of life across five dimensions — mobility, self-care, usual activities, pain and discomfort, and anxiety and depression — using a three-level response format that generates both a health state profile and a summary index value. It also includes a Visual Analogue Scale on which patients rate their overall health on a scale from zero to one hundred. The EORTC QLQ-C30 adds a further layer of cancer-specific quality of life measurement, covering functional scales (physical, role, cognitive, emotional and social functioning), symptom scales (fatigue, nausea, pain) and global health status. Together, these instruments provide a comprehensive, validated profile of patient health and wellbeing that can be benchmarked against national and international norms.

The Three Open Questions

The SIA EQ-5D Plus adds three open patient-narrative questions to the structured measurement instruments. These questions invite patients to describe, in their own words, the most important aspects of their recent experience of cancer care: what has gone well, what could have been better and what has had the greatest impact on their quality of life. The open questions are deliberately broad and patient-centred, giving respondents the freedom to identify the issues that matter most to them rather than being constrained to respond to investigator-defined categories. This is methodologically important: patients consistently identify concerns that structured instruments do not anticipate, and the open questions ensure that the intelligence generated by the SIA EQ-5D Plus reflects the full breadth of patient experience.

The combination of structured measurement and open narrative within a single instrument creates a powerful analytical opportunity. The structured component provides the quantitative anchor — the measurable outcomes data that allows for benchmarking, trend analysis and statistical comparison. The open narrative component provides the explanatory depth — the

patient-reported account of the specific experiences that produced those outcomes. When both components are analysed together, the result is an intelligence picture that is simultaneously rigorous and humanly grounded: precise enough to identify where quality of life is poorest and rich enough to explain why.

Deployment and Data Collection

The SIA EQ-5D Plus is deployed at clinically defined points along the cancer care pathway — at diagnosis, during active treatment, at the completion of treatment, and at defined intervals post-treatment. This longitudinal design means that quality of life trajectories can be tracked over time, and that changes in patient experience — both improvements and deteriorations — can be identified and attributed to specific stages of the pathway. The instrument is available in both digital and paper formats, ensuring accessibility for patients with varying levels of digital literacy, and it is supported by clear guidance for clinical and administrative staff responsible for its administration.

Data collected through the SIA EQ-5D Plus flows into the programme analytics platform, where it is integrated with CareOpinion data and CQOLS benchmarking information. The platform applies the AI-driven text analytics pipeline described in Chapter Three to the open narrative responses, extracting themes, sentiment and significance scores that can be mapped against the structured quality of life data to reveal the relationships between patient experience and patient outcomes. The result is a continuously updated intelligence picture at Trust, Cancer Alliance and ICB level, accessible to the clinical, operational and commissioning teams who need it.

Chapter 3
CareOpinion and Patient Narrative at Scale

The National Patient Narrative Platform

CareOpinion is a national, independently operated platform through which patients and their families can share detailed accounts of their healthcare experiences. Unlike conventional feedback mechanisms, CareOpinion is designed to facilitate genuine, narrative-rich accounts rather than structured survey responses: patients describe their experiences in their own words, in as much or as little detail as they choose, and their accounts are published publicly alongside the responses of the services involved. The platform covers the full breadth of NHS provision, but cancer services generate a particularly significant volume of feedback, reflecting both the high patient contact that characterises cancer care and the intensity of the experiences — both positive and difficult — that patients frequently wish to share.

For the Patient Feedback and Experience Intelligence Programme, CareOpinion represents a major and largely underutilised intelligence resource. The narrative richness of CareOpinion posts — the specificity with which patients describe individual interactions, clinical decisions, communication failures and emotional experiences — is precisely the kind of qualitative data that complements and contextualises the quantitative outputs of CQOLS. When analysed at scale using AI-driven text analytics, CareOpinion data reveals patterns that are invisible in any individual post but clearly discernible across hundreds or thousands: the recurring themes that indicate systemic service failures, the consistent sentiment signals that identify where patient experience is consistently poor and the specific operational concerns that represent the highest-priority targets for service improvement.

The Scale of Available Intelligence

Systematic analysis of national CareOpinion data for cancer services demonstrates the scale of the intelligence available. Analysis of over 114,000 sentences from cancer patient comments — a dataset of substantial size and analytical value — reveals clear and consistent patterns of concern. The highest-volume area of patient feedback relates to Diagnosis Experience, which accounts for more than a quarter of all cancer patient comments on the platform. Within this category, nearly 70 percent of sentiment is negative, reflecting the profound distress that patients experience during the diagnostic phase and the frequency with which the specific handling of the diagnostic process — the communication of results, the management of waiting, the explanation of what a diagnosis means — falls short of what patients need.

Two other areas merit particular attention for the scale and consistency of negative sentiment they attract. Timeliness and Responsiveness generates the most consistently negative responses of any category, with more than 72 percent of relevant comments expressing

negative sentiment. Patients describe waits that feel unreasonable and unexplained, referral processes that appear slow or poorly coordinated and responses to clinical concerns that arrive later than patients feel their situation warrants. Infection Control, though lower in volume, generates the highest proportion of negative sentiment of any category — nearly 74 percent — reflecting patient concerns about hygiene standards, isolation procedures and the management of infection risk in clinical environments.

From Comments to Actionable Intelligence

The transformation of CareOpinion narrative into actionable intelligence requires a systematic approach that goes beyond manual review. Individual posts can be read, considered and responded to by clinical teams — and this remains valuable, not least because the public response to individual posts demonstrates organisational responsiveness and can itself influence patient confidence. But the intelligence value of CareOpinion at scale is realised only through consistent, analytically structured processing that can identify patterns across thousands of posts simultaneously. The AI-driven text analytics pipeline described in Chapter Four provides this capability, making CareOpinion data analytically tractable at a level that manual review cannot achieve.

The output of this analysis is not simply a list of themes but a structured intelligence product: a ranked assessment of the areas of highest concern by theme, volume and sentiment, accompanied by representative illustrative comments that give the quantitative patterns a human face. This intelligence product is designed to be interpretable by clinical and operational teams without statistical expertise, and to be directly actionable — pointing clearly to the specific service aspects that require attention and providing the evidence base for prioritising improvement effort.

Chapter 4
AI-Driven Text Analytics: The Analytical Engine

The Challenge of Unstructured Patient Data

Open patient narrative — whether from CareOpinion, from the open questions of the SIA EQ-5D Plus or from patient forum discussions and post-treatment questionnaires — is inherently unstructured. Unlike survey ratings or clinical outcome scores, it does not arrive pre-formatted for analysis. It is written in natural language, with all the variability, ambiguity and emotional texture that characterises human communication. Patients use different words to describe the same experience; they embed important clinical information within personal narrative; they express complex, mixed feelings about care that was partly positive and partly deeply problematic. Extracting consistent, comparable intelligence from this material at scale is a challenge that exceeds the capacity of manual approaches.

AI-driven text analytics — specifically, the application of natural language processing methods to analyse patient narrative at volume — makes this challenge tractable. The analytical pipeline used by the Patient Feedback and Experience Intelligence Programme processes patient narrative through three sequential stages: theme detection, sentiment classification and significance scoring. Each stage builds on the previous, transforming raw text into structured intelligence that can be aggregated, compared and visualised. The result is a capability that can analyse thousands of patient comments in minutes, with a consistency and reproducibility that manual review cannot achieve, while preserving enough contextual sensitivity to capture the nuance that matters for clinical interpretation.

Theme Detection

Theme detection is the first stage of the analytics pipeline. The system applies a combination of trained classification models and semantic clustering methods to identify the primary subject matter of each piece of patient narrative — the aspect of care the patient is describing. The theme taxonomy is structured to reflect the clinical and operational dimensions of cancer care that matter most: diagnostic experience, treatment delivery, side effect management, communication and information, follow-up and aftercare, emotional and psychological support, coordination across services, access and timeliness and practical support. Within each theme, a richer sub-theme structure captures the specific aspects that patients most commonly address.

The theme detection stage produces a tagged dataset in which each piece of patient narrative is associated with one or more primary themes and, where relevant, one or more sub-themes. This tagging structure allows the subsequent analytical stages to be applied at the level of granularity that is most useful for action: not simply "patients are concerned about communication" but "patients receiving post-treatment follow-up are concerned about

inconsistent information from different clinical staff about what symptoms require urgent attention." The specificity of this intelligence is what makes it actionable.

Sentiment Classification and Significance Scoring

The second analytical stage is sentiment classification. For each piece of tagged narrative, the system assigns a sentiment score reflecting whether the patient is expressing a positive experience, a negative experience or a mixed experience in relation to the identified theme. Sentiment classification uses models trained on healthcare-specific language, ensuring that the emotional register of clinical communication — which differs significantly from the language used in consumer feedback or social media — is interpreted accurately. The output is a sentiment distribution for each theme: the proportion of comments that are positive, negative and mixed, and the intensity of sentiment in each direction.

The third stage is significance scoring. Not all negative sentiment is equally important. A comment expressing mild dissatisfaction with car parking arrangements, while a legitimate piece of feedback, does not carry the same clinical significance as a comment describing a failure to communicate a cancer diagnosis clearly or a breakdown in infection control procedures. The significance scoring system weights sentiment by theme, volume and clinical relevance, producing a ranked list of the issues that most urgently require attention. This ranking is the primary output that reaches clinical and operational teams, ensuring that their attention is directed to the areas of highest impact rather than to the loudest or most numerous complaints.

Integration with CQOLS and Structured Data

The output of the text analytics pipeline is designed to be read in conjunction with CQOLS quality of life data and the structured outcomes data from the SIA EQ-5D Plus. Where the text analytics identifies a theme with consistently high negative sentiment — unmet emotional support needs, for example — this finding is cross-referenced against the CQOLS data to identify whether anxiety and depression scores for the same patient population are elevated relative to national benchmarks. Where there is concordance — where both the qualitative and the quantitative evidence point in the same direction — the intelligence is considerably more robust and the case for action considerably stronger. This integration of qualitative and quantitative evidence is one of the most distinctive features of the programme and a significant source of its analytical power.

Chapter 5
Evidence from Patient Experience Analysis

The Experience of Post-Treatment Abandonment

One of the most consistent and clinically significant themes to emerge from systematic analysis of cancer patient feedback is what patients themselves describe as a sense of abandonment at the end of active treatment. The experience is characterised with striking consistency across different patient populations, different cancer types and different service settings. A patient reflecting on her cancer experience in a structured feedback exercise expressed it in terms that have become emblematic of a much wider pattern: "I felt forgotten after treatment." The words are simple, but the experience they describe is complex and consequential.

Post-treatment abandonment, as patients describe it, is not simply a matter of reduced contact with clinical services — though this is itself frequently experienced as abrupt and poorly managed. It encompasses a broader set of experiences: the loss of the structure and certainty that intensive treatment provides; the absence of clear information about what to expect in the weeks and months after treatment ends; inadequate guidance about which symptoms are normal, which represent potential complications requiring medical attention and which indicate recurrence requiring urgent review; and a pervasive sense that the services that mobilised so effectively around the crisis of diagnosis and treatment have disengaged just when the psychological and practical challenges of living beyond cancer are at their most acute.

Communication Failures Across the Pathway

A second major theme from patient feedback analysis is the pervasiveness and diversity of communication failures across the cancer care pathway. Patients describe communication problems that begin at the point of diagnosis and persist through treatment and into follow-up. During the diagnostic phase — which analysis of CareOpinion data confirms as the highest-volume area of cancer patient feedback, generating more than 27 percent of all comments — patients frequently describe delays in the communication of diagnostic results, inconsistency between what different clinical staff tell them, inadequate explanation of what a positive diagnosis means and what will happen next, and a sense of being processed by a system that is clinically proficient but humanly insufficient.

During treatment, communication failures take different forms. Patients describe inadequate preparation for the side effects of treatment, both immediate and longer-term — a failure that can mean they are caught entirely unprepared by consequences that clinical teams might have anticipated and should have discussed. They describe inconsistent information from different members of the clinical team, creating uncertainty and anxiety at a time when clarity and

consistency are most needed. They describe difficulty accessing clinical staff when concerns arise between appointments, and delayed responses when they do manage to make contact. These failures, taken individually, might appear to reflect the operational pressures of an under-resourced system. Taken together, as systematic analysis reveals them to do, they indicate a structural deficit in the way communication is designed and managed across the cancer care pathway.

Unmet Physical and Emotional Support Needs

Analysis of patient feedback — particularly from structured open-question responses and patient forum discussions — consistently identifies large unmet needs in both physical and emotional support. In the physical domain, patients describe fatigue and loss of energy that is more persistent and more debilitating than they were led to expect; weight changes and changes in body composition that affect their sense of self and their functional capacity; sexual health consequences that are significant in their impact on wellbeing and relationships but rarely addressed proactively by clinical services; and a general deficit in access to rehabilitation and self-management support that might help them to recover function more effectively and maintain it over time.

In the emotional and psychological domain, the picture is equally consistent. Patients describe anxiety that persists well beyond the end of active treatment — anxiety about recurrence, about the long-term consequences of treatment and about what the experience of cancer means for their future. They describe depression and low mood that goes unrecognised and unsupported by clinical services. They describe the social and relational consequences of a cancer experience that has changed them in ways that others around them do not always understand or acknowledge. And they describe the specific emotional burden of "scanxiety" — the anxiety associated with follow-up imaging and the waiting period between scan and result — as a recurring feature of post-treatment life that the system does little to address.

Operational Concerns: Timeliness and Infection Control

Beyond the clinical and relational themes, patient feedback analysis also identifies operational concerns that are both practically significant and clinically relevant. Timeliness and responsiveness is the most consistently negatively-rated operational dimension in cancer patient feedback, with national CareOpinion analysis showing that more than 72 percent of relevant comments express negative sentiment. This figure is higher than many NHS quality leads and patient experience teams may appreciate, because the timeliness concerns that patients most frequently describe — delays in receiving test results, waits for follow-up appointments, delayed responses to clinical queries — are not always captured by the waiting time metrics that routine NHS monitoring systems track.

Infection control generates the highest proportion of negative sentiment of any area in cancer patient feedback analysis — nearly 74 percent of relevant comments. This reflects patient awareness of the particular infection risks they face during and after treatment, and their concern about the rigour with which clinical environments manage those risks. For cancer patients, many of whom are immunocompromised during treatment, infection represents a genuine and serious threat. The consistency and intensity of negative sentiment on this issue

suggests that patient perceptions of infection control standards in cancer care settings deserve more systematic attention than they currently receive.

Chapter 6
Integrating Feedback with CQOLS Benchmarking

The Intelligence Integration Framework

The full analytical power of the Patient Feedback and Experience Intelligence Programme is realised when the qualitative intelligence generated by patient narrative analysis is integrated with the quantitative benchmarking intelligence provided by CQOLS. This integration is not simply a matter of presenting two sources of data side by side. It requires an active interpretive framework — a structured approach to identifying the connections between what patients report in their own words and what the validated quality of life instruments measure — and a communication methodology that presents the integrated intelligence in a form that clinical and operational teams can readily understand and act upon.

The integration framework operates on the principle that CQOLS quality of life domains map systematically to the thematic areas identified by patient narrative analysis. The CQOLS anxiety and depression domain maps to the emotional support and psychological wellbeing themes in patient feedback. The CQOLS pain and discomfort domain maps to feedback themes around symptom management and treatment side effects. The CQOLS usual activities domain maps to feedback themes around rehabilitation, functional recovery and self-management support. The CQOLS social participation domain maps to feedback themes around post-treatment isolation, communication support and the social consequences of cancer. These mappings are not perfect — the relationship between subjective experience and reported quality of life is complex — but they provide a structured basis for interpreting the two sources of evidence in relation to each other.

From Correlation to Understanding

The practical benefit of this integration framework is that it enables NHS organisations to move from correlation to understanding. Without the integration, an organisation might know from CQOLS data that its patients report below-average emotional wellbeing scores and know from patient feedback analysis that emotional support is a theme with consistently high negative sentiment — but the connection between these two observations would be implicit rather than explicit, and its implications for action would be unclear. With the integration framework, the connection is made explicit: elevated emotional distress in CQOLS scores, combined with consistently negative feedback on emotional support provision, indicates a specific and addressable gap in service provision.

This specificity is what transforms intelligence from analytically interesting to operationally useful. An organisation that knows its CQOLS anxiety scores are above the national median has a data point. An organisation that knows its CQOLS anxiety scores are above the national median and that patient feedback consistently identifies inadequate post-treatment follow-up

communication as the most significant contributor to patient anxiety has an action agenda. The integration framework is the mechanism that makes the second situation possible from the first.

Benchmarking at Multiple Levels

One of the most valuable features of the integrated intelligence framework is that it can operate at multiple levels simultaneously. At Trust level, the integration of local patient feedback with Trust-specific CQOLS data provides an intelligence picture that is directly relevant to local quality improvement: identifying the specific service aspects at a particular Trust that are most strongly associated with the quality of life outcomes its patients report. At Cancer Alliance level, the integration of aggregated feedback and CQOLS data across member Trusts allows system-level patterns to be identified — themes that are consistently problematic across multiple sites, areas where one Trust performs markedly better than others providing a model for learning, and priorities for system-level intervention.

At ICB level, the integrated intelligence provides the commissioning evidence base for strategic service redesign. An ICB that can demonstrate, using both qualitative and quantitative evidence, that post-treatment emotional support services are consistently inadequate across its cancer care providers — and that this inadequacy is associated with measurably lower quality of life outcomes for cancer survivors — has a much stronger foundation for commissioning decisions than one that relies on either source of evidence alone. The integration framework makes this multi-level analytical capability possible within a single, coherent system.

Chapter 7
Roles and Responsibilities

A Shared Responsibility Architecture

The Patient Feedback and Experience Intelligence Programme operates across multiple levels of the NHS cancer system, and its success depends on clear allocation of roles and responsibilities at each level. The programme is not owned exclusively by any single type of organisation, nor is it the responsibility of any single professional group. It is, rather, a shared infrastructure — one that requires active contribution and engagement from Trusts, Cancer Alliances, ICBs and the national programme team, each playing a distinct role in a mutually reinforcing system.

The national programme team is responsible for the design, maintenance and development of the overall framework: the analytics platform, the SIA EQ-5D Plus instrument, the reporting standards and the integration methodology that connects local intelligence to national benchmarking. The national team should also manage the CareOpinion AI text analytics infrastructure, ensuring that the AI-driven analytics pipeline is applied consistently across all participating organisations and that the output meets the quality and accessibility standards needed for operational use. It provides training, support and quality assurance to ensure that the programme is implemented consistently and effectively across the system.

Trust-Level Roles

At Trust level, the primary responsibilities are data collection, local interpretation and local action. The Trust cancer patient experience lead — a role that may be held by a nurse consultant, a quality improvement lead or a dedicated patient experience professional — should be responsible for ensuring that the SIA EQ-5D Plus is administered systematically at the defined pathway points, that response rates meet the minimum thresholds required for reliable analysis and that the intelligence outputs reach the clinical and operational teams who need them. The Trust patient experience lead also leads the local interpretation of intelligence outputs, working with clinical teams to contextualise the analytical findings against their understanding of local service provision and to identify the most appropriate improvement responses.

Clinical teams at Trust level have a responsibility to engage actively with patient experience intelligence — to treat it not as an external imposition but as a source of evidence about the quality of the care they provide. This engagement requires both the willingness to receive feedback that is sometimes challenging and the capacity to respond constructively. The programme supports this engagement by presenting intelligence in forms that are clinically accessible and operationally relevant, and by providing improvement support resources that connect the intelligence outputs to evidence-based service improvement interventions.

Cancer Alliance and ICB Roles

Cancer Alliance teams play a pivotal role in the intelligence ecosystem the programme creates. The Cancer Alliance receives aggregated and comparative intelligence across its member Trusts, enabling it to identify system-level patterns, to support benchmark-informed conversations with Trust teams and to deploy its quality improvement capacity where intelligence indicates it is most needed. Cancer Alliance teams are also well placed to identify examples of excellent local practice that can be shared across the system — instances where a Trust is performing significantly better than its peers on a particular dimension of patient experience, and where understanding how that performance has been achieved could benefit other organisations.

ICBs should engage with the programme primarily through its commissioning implications. The integrated intelligence framework provides ICBs with the evidence base they need to make informed commissioning decisions about cancer survivorship services, psychological support provision, rehabilitation services and the other service elements that patient feedback and CQOLS data consistently identify as most critical to quality of life outcomes. By making the relationship between service quality and patient outcomes explicit and quantified, the programme strengthens the case for investment in the support services that are most likely to improve outcomes and reduce downstream system costs.

Chapter 8
Reporting, Governance and Continuous Improvement

The Reporting Framework

The Patient Feedback and Experience Intelligence Programme produces intelligence at three levels: real-time operational monitoring, periodic thematic reporting and strategic annual review. The real-time monitoring layer provides continuously updated dashboards that track the volume, sentiment and thematic distribution of incoming patient feedback — enabling clinical and operational leads to detect emerging patterns as they develop rather than discovering them retrospectively. This layer is designed to support rapid response: if a new theme of concern begins to appear consistently in patient feedback, the monitoring system surfaces it in near-real-time, enabling teams to investigate and respond before the pattern has time to become entrenched.

The periodic reporting layer produces structured intelligence reports at quarterly and six-monthly intervals, providing the more detailed, analytically processed account of patient experience that informs quality improvement planning. These reports present the quantitative intelligence — theme volumes, sentiment distributions, significance rankings — alongside the integrated CQOLS comparison that connects feedback patterns to quality of life outcomes. They are designed to be the primary intelligence input for Trust cancer board discussions, Cancer Alliance quality improvement conversations and ICB commissioning review processes.

Governance and Quality Assurance

Governance of the programme operates at both national and local levels. Nationally, an oversight group comprising representatives of Trusts, Cancer Alliances, ICBs, patient representative organisations and the national programme team should establish reviews of the analytics methodology, monitor implementation quality and approves any significant changes to the programme framework. This group should meet quarterly and receive the programme quality assurance report, which covers response rates, data completeness, analytics reliability and implementation fidelity across participating organisations.

Locally, governance is exercised through the existing quality and governance structures of participating organisations — cancer boards, patient experience committees and equivalent bodies. The programme provides standardised governance documentation and a clear accountability framework to support local governance bodies in fulfilling their oversight function effectively. Patient representative involvement in governance is a requirement of the programme rather than an optional enhancement: the patient voice that the programme is designed to amplify must be present in the structures that oversee how that voice is heard and acted upon.

Closing the Loop: From Intelligence to Improvement

The test of any patient intelligence programme is not the quality of the intelligence it produces but the quality of the improvements it drives. The Patient Feedback and Experience Intelligence Programme includes a structured improvement tracking mechanism — the 90-day action plan framework — that connects each significant intelligence output to a specific improvement commitment with a defined owner, a time-bound delivery plan and measurable outcome indicators. Organisations that receive intelligence identifying a significant concern are expected to respond with a 90-day action plan within a defined period, and to report back on progress against that plan at the next quarterly review.

This closing-the-loop mechanism is the point at which patient intelligence becomes patient benefit — the point at which the words patients have shared about their experiences translate into changes in how care is delivered. It is also, crucially, the point at which the programme justifies the investment it represents. Patient feedback collected, analysed and not acted upon is not simply wasted: it is a source of legitimate patient frustration, an indication that the system is not listening even when patients speak. The 90-day action framework ensures that listening is followed by response, and that the programme contributes genuinely to the improvement of care.

Chapter 9
Conclusion: Towards a Unified Patient Intelligence System

A Convergence of Capability and Opportunity

We are at a pivotal moment in the development of patient intelligence in NHS cancer care. For the first time, the combination of validated quality of life measurement, digital patient narrative platforms, AI-driven text analytics and national benchmarking infrastructure has made it genuinely possible to understand cancer patient experience with the depth, consistency and precision that meaningful quality improvement requires. The capability now exists to move from a model in which patient feedback is collected and filed to one in which it is continuously analysed, integrated with clinical outcomes evidence and translated into targeted, evidence-based action. The Patient Feedback and Experience Intelligence Programme is the vehicle for making that transition.

The opportunity this transition represents is not simply technical. It is a strategic, clinical and ethical opportunity to honour the act of patients sharing their experiences by ensuring those experiences actually shape the care that follows. Every patient who describes feeling forgotten after treatment, every patient who identifies a communication failure that left them anxious and uninformed, every patient who reports an unmet emotional support need or a physical consequence of treatment that was never anticipated or addressed — each of these patients has done something that requires a response: they have trusted the NHS with an account of where it has fallen short. The question this programme answers is how the NHS builds the systems and the culture to ensure that trust is warranted — that the feedback is genuinely heard, systematically understood and acted upon.

The Power of Connecting What and Why

The central analytical insight of this programme — that CQOLS tells us what patients are experiencing while patient narrative feedback tells us why — is more than an interesting methodological observation. It is the foundation of a new kind of clinical intelligence that neither quality of life measurement alone nor patient experience feedback alone can provide. CQOLS, for all its analytical power and methodological rigour, cannot by itself explain why its measurements show what they show. It can identify that patients in a particular service report elevated anxiety and reduced social participation relative to national norms, but it cannot identify whether this reflects inadequate follow-up communication, insufficient access to psychological support, poor coordination between primary and secondary care or some combination of these. Without the explanatory 'why', the 'what' is difficult to act on.

Patient feedback, conversely, provides rich explanatory narrative — the specific, humanly grounded accounts of what went wrong, what could have been better and what mattered most — but without the quantitative anchor of validated outcomes measurement, it is difficult to

know how representative any individual account is, how severe the problems it describes are relative to other settings and whether the issues it identifies are producing measurable harm. The integration of both sources of intelligence, within the analytical framework this programme provides, resolves both limitations simultaneously. The result is not simply better data but better understanding: a comprehension of cancer patient experience that is both measurably precise and humanly grounded.

What the Evidence Already Tells Us

The intelligence that has already emerged from the application of this programme's analytical approach to existing patient feedback data is both sobering and instructive. It is sobering because it reveals the scale of the unmet need that currently characterises cancer care: the tens of thousands of patients experiencing a sense of abandonment at the end of active treatment; the systematic communication failures that leave patients anxious, uninformed and uncertain across the cancer pathway; the emotional support deficit that allows depression and anxiety to persist unrecognised and unaddressed in patient populations whose quality of life could be substantially better; and the operational concerns around timeliness and infection control that patients identify with a consistency that demands serious attention.

It is instructive because the intelligence is specific enough to act on. The post-treatment abandonment theme is not simply a generalised expression of dissatisfaction; it is a precise description of a specific service gap — the transition from active treatment to post-treatment follow-up — that could be addressed through a defined set of interventions: structured end-of-treatment reviews, personalised care plans communicated to patients in clear and accessible language, proactive follow-up contacts at defined intervals, clear and consistently communicated guidance on which symptoms require urgent attention. The emotional support deficit is not simply a feeling that things could be more compassionate; it is a measurable gap in provision — of access to psychological support services, of proactive screening for distress during and after treatment, of the kind of peer support and community connection that cancer survivors consistently identify as valuable — that commissioning decisions could address.

The Specific Signals that Demand Response

Among the themes that patient feedback analysis has consistently surfaced, several deserve particular emphasis as priorities for NHS action. The first is the experience of post-treatment limbo — the period after active treatment ends when patients feel most isolated, most uncertain and least supported, and when the gap between the support they receive and the support they need is at its widest. The phrase 'I felt forgotten after treatment' is not the expression of one patient but the distilled experience of many thousands. It describes a failure of care transition that is systemic, predictable and, importantly, preventable. Structured, proactive end-of-treatment pathways — developed in partnership with patients and communicated clearly from the moment of diagnosis — would substantially reduce the experience of post-treatment abandonment.

The second priority signal is the sexual health and intimate relationship consequences of cancer treatment, which patient feedback analysis consistently identifies as one of the most significant and least adequately addressed domains of survivorship care. Patients across

multiple cancer types and multiple treatment modalities describe sexual health consequences — loss of libido, sexual dysfunction, changes in body image and intimate relationship difficulties — that they were not adequately prepared for and for which clinical support is rarely proactively offered. CQOLS social participation and emotional functioning data supports this picture: patients who report sexual health concerns tend also to report lower scores on the social and emotional quality of life scales. The convergence of qualitative and quantitative evidence on this issue is clear, and the case for proactive sexual health support as a standard element of cancer survivorship care is correspondingly strong.

The third priority signal is the digital fragmentation that patients describe in their experience of navigating information and support. Multiple patients have described an experience of being directed to different digital platforms, patient information resources and online communities by different members of their clinical team, with no consistent signposting, no integration between sources and no recognition that the proliferation of fragmented digital resources can add to patient burden rather than reducing it. For cancer patients — particularly older patients, those with lower digital literacy and those managing the cognitive and physical fatigue that cancer treatment produces — fragmented digital information is not a minor inconvenience but a significant barrier to self-management and to accessing the support they need.

Linking Intelligence to Action: The 90-Day Opportunity

The 90-day action plan framework embedded in this programme is designed to ensure that patient intelligence translates reliably into service improvement. It is the mechanism through which the analytical work of the programme produces its ultimate justification: better care. The framework is structured around three questions: What does the intelligence indicate needs to change? Who is responsible for making that change? And how will we know whether the change has worked? These questions are deceptively simple but operationally essential. Without clear answers to all three, even the best patient intelligence tends to generate discussion rather than action.

National analysis of CareOpinion data, West Suffolk patient forum feedback and prostate support group structured responses all illustrate what the 90-day framework can achieve when applied with organisational commitment. The CareOpinion analysis identifies specific, actionable concerns — Diagnosis Experience communication failures, Timeliness issues, Infection Control concerns — that can be mapped to specific interventions with measurable outcome indicators: the proportion of patients who rate their experience of receiving a diagnosis as positive, the proportion of time-sensitive referrals completed within defined windows, the proportion of patients who rate infection control standards as adequate. Each of these indicators can be tracked through the programme's analytics infrastructure, creating a feedback loop between intelligence, action and outcome that is the hallmark of a genuine learning system.

The Role of CQOLS in Amplifying Patient Voice

CQOLS is the quantitative backbone of the Patient Feedback and Experience Intelligence Programme, but its role in this context goes beyond data provision. It functions as an

amplifier of patient voice — a mechanism through which the experiences patients describe in their own words are given the analytical weight of validated, nationally benchmarked measurement. When a patient describes unmet emotional support needs in a post-treatment questionnaire, that account is one person's experience. When CQOLS data shows that the Trust to which that patient belongs reports anxiety and depression scores that are statistically significantly above the national median, the account becomes evidence. The combination elevates individual feedback from anecdote to intelligence and makes the case for action impossible to dismiss.

At Trust level, the combination of CQOLS benchmarking and patient feedback analysis creates the kind of granular, actionable intelligence that clinical governance processes require: not simply "we are below average on this measure" but "we are below average on this measure, and patient feedback consistently identifies this specific service gap as the most likely explanation." At Cancer Alliance level, the same combination enables system-level learning: identifying the Trusts where the combination of good CQOLS performance and positive patient feedback represents a model worth understanding and replicating, and those where persistent underperformance on both dimensions indicates a need for targeted improvement support. At ICB level, the intelligence provides the commissioning evidence that connects resource allocation decisions to measurable patient outcomes.

Building a Culture of Patient Intelligence

The technical and analytical capabilities this programme provides are necessary but not sufficient. Sustaining the improvement potential they represent requires a cultural shift in how NHS cancer organisations relate to patient feedback — a shift from treating it as a compliance activity to treating it as a strategic intelligence function that is as central to organisational performance as clinical audit, financial reporting or workforce planning. This cultural shift requires leadership visibility: senior clinical and operational leaders who demonstrably engage with patient intelligence, who model the kind of reflective, improvement-focused response to feedback that they want their organisations to embed, and who make clear that acting on what patients tell them is a professional and organisational priority rather than an optional extra.

It also requires patient partnership — not as a gesture towards co-production but as a genuine organisational commitment to involving patients in the design, interpretation and governance of the intelligence systems that are, ultimately, about their care. The most effective patient experience programmes are those in which patients are involved not simply as subjects of data collection but as partners in the analytical and improvement process: helping to define the questions the analysis addresses, contributing to the interpretation of findings, validating the improvement responses that organisations develop and tracking whether those responses have made a difference that patients can actually feel. The programme's governance framework reflects this commitment, but its realisation depends on the active engagement of participating organisations.

The Integrated Patient Intelligence Vision

Looking forward, the Patient Feedback and Experience Intelligence Programme points towards a vision of patient intelligence in NHS cancer care that is substantially more integrated, more continuous and more actionable than anything currently available. In this vision, every cancer patient contributes to a continuously updated intelligence picture through the feedback they provide — whether through structured instruments like the SIA EQ-5D Plus, through narrative platforms like CareOpinion or through the growing range of digital patient-reported outcome tools that are becoming available. That intelligence is processed in near-real-time by AI-driven analytics, integrated with CQOLS benchmarking and presented to clinical, operational and commissioning teams in forms that are immediately actionable.

The gaps that patients consistently identify — post-treatment support deficits, communication failures, emotional support inadequacies, operational concerns about timeliness and infection control — are addressed not reactively but proactively, because the intelligence that reveals them is available continuously rather than periodically. The improvements that result are tracked and validated through the same quality of life and patient experience measures that identified the problems in the first place, creating a genuine learning loop in which patient voice drives continuous improvement. Cancer services become, in this vision, genuinely patient-intelligent systems: organisations that know, at any given moment, what the people they serve are experiencing, why they are experiencing it and what needs to change.

A Call to Action

The NHS has never lacked patient feedback. What it has sometimes lacked is the analytical infrastructure, the interpretive framework and the organisational commitment to make that feedback count. The Patient Feedback and Experience Intelligence Programme addresses each of these gaps directly. The analytical infrastructure is in place. The interpretive framework — the systematic integration of patient narrative with CQOLS quality of life benchmarking — has been designed, tested and is operational. The organisational commitment is now required.

Every Trust, Cancer Alliance and ICB that engages with this programme is making a practical commitment to the patients in its care: a commitment that what they share about their experiences will be heard, that it will be understood in the context of the measurable outcomes evidence that validates its significance and that it will result in specific, tracked improvement actions. It is a commitment, in short, to treat the patient voice not as a data source but as a partner in the work of building better cancer care. There is no more important use of the intelligence available to the NHS cancer system than this. And there has never been a better time to begin.