Silicon Practice
DIGITAL HEALTH SOLUTIONS

SUPPORTING PATIENTS BETWEEN APPOINTMENTS: A DIGITAL GUIDE FOR CANCER SUPPORT TEAMS

A practical support pack

2026

Table of Contents

Why this guide exists 03

Why anxiety peaks between appointments 04

Common information gaps patients face 05

The impact on services and staff 06

How digital support can help, and what it should not try to do 07

The misinformation problem, and why trusted content matters 08

Supporting emotional wellbeing between appointments 09

Symptom tracking and side-effect support that actually helps 10

Carers: support the wider care unit, not only the patient 11

A simple framework for designing a digital patient journey 12

Getting started without adding burden 13

Common objections, and how to address them 14

Contact 14

Why this guide exists



"Cancer affects us all. Delivering the best outcomes for cancer patients is an absolute priority; we want every person with cancer to have the very best diagnosis, treatment and care."

NHS England

The space between appointments can feel like a void for patients and carers. Symptoms shift, worries grow legs, questions multiply, and the "right" contact route can be unclear. Even in excellent services, the gaps between touchpoints are where uncertainty lives. It is often in these moments, late at night, between letters, or while waiting for results, that anxiety peaks and confidence dips.

For many patients, this in-between time becomes a balancing act. They are trying to decide what is normal, what can wait, and what needs attention now, often without reassurance or context. Carers are left second-guessing themselves too, unsure whether to encourage rest, escalate concerns, or simply sit tight. Small uncertainties can quickly feel overwhelming when there is no obvious place to turn.

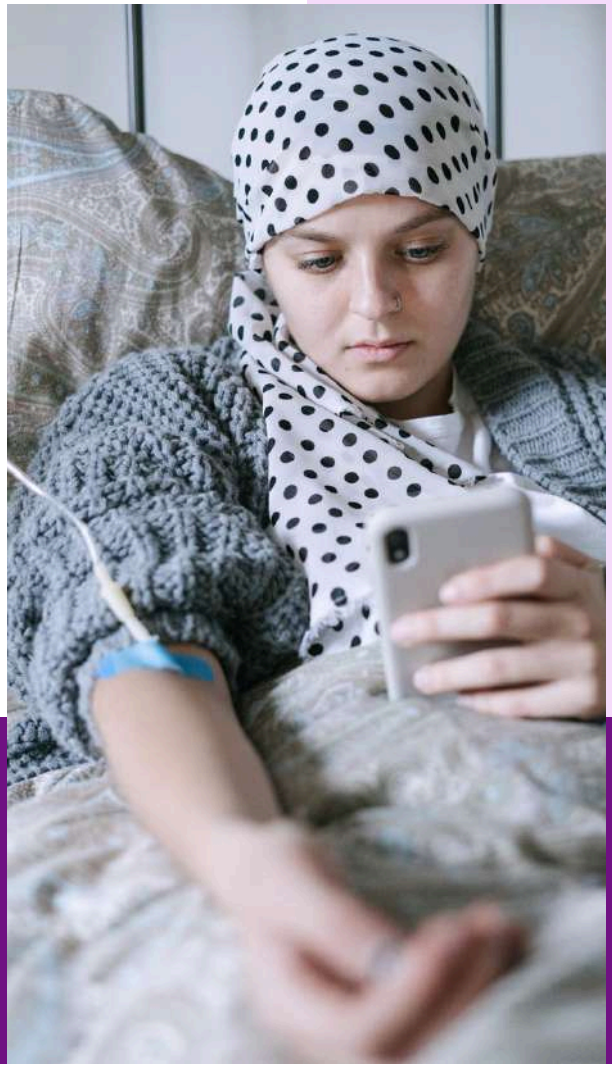
This guide is designed to help cancer support teams strengthen that in-between time using practical, patient centred digital support that complements clinical care. It focuses on tools that provide reassurance without replacing human contact, offering clarity, consistency and a sense of continuity between appointments.

You will explore approaches that help patients understand symptoms, access trusted information, know when and how to seek help, and feel supported even when they are not physically in clinic. The emphasis is on reducing avoidable distress, improving confidence and helping patients and carers navigate next steps with greater certainty.

Throughout the guide, we focus on what works in the real world. Simple, scalable digital support that fits into existing pathways, supports busy teams and responds to the reality that most patient experience happens outside the consultation room. The aim is not to add noise or burden, but to quietly strengthen the moments that matter most.

Why anxiety peaks between appointments

Cancer related anxiety is common, but the pattern often intensifies between scheduled contact points. That makes sense. When patients are in clinic, they have a plan, a clinician and a moment of containment. When they leave, they may be left with new information, side effects, waiting for results and a brain that is trying to protect them by scanning for threat.



What the evidence says

- A large meta-analysis in long term cancer survivors found anxiety prevalence of **17.9%** compared with **13.9%** in healthy controls, showing anxiety can persist well beyond active treatment
- A 2023 study using GAD-7 (a common anxiety measure) reported **13.8%** of cancer patients with moderate to severe anxiety (GAD-7 ≥ 10), and a 2.7-fold increased risk compared with the general population
- Anxiety is also strongly linked to points of uncertainty. Research on pre-visit anxiety in breast cancer shows anxiety and uncertainty can shape how patients process information and communicate with clinicians around appointments, which helps explain why worries can surge before and after contact points

Why between-appointment anxiety is different

Between appointments, patients often face a mix of:

- Uncertainty without immediate clarification, for example “Is this symptom expected?”
- Waiting, for results, treatment decisions, referral steps, scans, or next appointments
- Information overload, where a short appointment generates a long tail of questions
- Isolation, especially if family support is limited, or they are protecting loved ones
- Loss of control, which can make small physical sensations feel alarming

For support teams, the key is not to “fix anxiety” through digital tools, but to reduce unnecessary uncertainty and provide structured reassurance, next steps and clear routes to help. That is often what makes anxiety manageable.

Common information gaps patients face



Patients often leave appointments with unanswered questions, not because clinicians are not thorough, but because appointments are time-limited and the cognitive load is huge. Many people also struggle to absorb complex information while shocked, fatigued, or scared.

What the evidence says

- A 2024 patient-led survey on information and communication found **77%** wanted more prognostic information, and **99%** of patients without access to their records wanted access
- A 2025 Scientific Reports study found most respondents (**80.5%**) preferred to have as much information as possible about disease and treatment, and cited prior UK findings where **79%** to **94%** of cancer patients wanted more detailed information
- In a UK survey about care after cancer treatment, clinicians reported that follow-up most frequently addressed fatigue (**84%**), fear of recurrence (**83%**), anxiety (**82%**) and low mood (**78%**), highlighting how much of "what patients need" sits outside purely biomedical instructions

What this looks like day to day

Common gaps cancer support teams see include:

- **Symptoms and side effects**, what is normal, what is not, and what to do next
- **Medication clarity**, what to take, when, interactions, what to do if missed
- **Test results and timing**, what results mean and realistic expectations for timelines
- **Who to contact**, which number, which service, what counts as urgent
- **Self-management**, practical steps for fatigue, nausea, appetite, sleep, mouth care
- **Emotional and psychological support**, reassurance, coping strategies, signposting
- **Carer guidance**, how to help, what to look out for, how to cope themselves

The practical implication is simple: if you want to improve the between-appointment experience, you do not need to digitise everything. You need to identify your service's **"top 20 recurring questions"** and make the answers accessible, trusted and easy to act on.

The impact on services and staff

Between-appointment gaps do not just affect patient experience. They drive workload, reduce efficiency and can contribute to missed appointments, repeated reassurance conversations and avoidable escalation into urgent care when people cannot get timely clarity.



What the evidence says about missed contact and system costs

- In England, around **8 million** outpatient appointments were missed in 2017/18, with each costing about £120, implying close to **£1 billion** in missed outpatient appointment costs
- NHS England reported a pilot that reduced DNAs by almost a third in six months using predictive tools and targeted intervention, reinforcing that system design and communication can influence attendance

Those figures are not cancer-specific, but they matter because cancer pathways involve multiple outpatient touchpoints. When communication and confidence are poor, attendance and preparedness can suffer.

What the evidence says about call burden

Telephone workload in oncology services has been studied for years. For example, an ambulatory oncology study quantified telephone calls and their distribution, highlighting that calls are a significant part of workload in many services.

The take-away is not that "digital equals fewer calls" in every setting. It is that **calls are often a symptom of missing clarity**, and when you fill those gaps with trusted guidance and structured routes to help, you can reduce unnecessary contacts and make necessary contacts more efficient.

Where digital support helps in practice

Digital support can reduce strain when it:

- Reduces repeated "Where do I find…" and "Is this normal…" contacts
- Prepares patients for appointments so contact time is higher value
- Encourages the right contacts at the right time, for example urgent symptoms
- Helps patients remember what was agreed and what happens next
- Gives carers information so they do not need to chase separately

Even small interventions, like clearer "when to call" guidance and appointment reminders, can have outsized effects at scale.

How digital support can help, and what it should not try to do

A good patient-facing cancer journey app is not a dumping ground for PDFs. It is a structured, empathetic layer that helps patients and carers navigate their reality day to day.



Two important principles

1. **Complement, do not replace.** Digital support should make it easier to access human care appropriately, not act as a barrier
2. **Reduce cognitive load.** Patients should not have to work hard to interpret or find information

What the evidence says about information access

The 2024 survey showing **99%** of patients without record access wanted it suggests a strong appetite for accessible information and clarity.

This is relevant because “access” is not only about clinical records. It is about **practical access to what you need to know, when you need to know it.**

What digital support does well

- Provides on-demand, consistent, trusted information, reducing reliance on random searching
- Supports self-management and coping with bite-sized guidance
- Enables structured symptom tracking that helps patients describe issues clearly
- Offers reminders and prompts that reduce missed steps and missed appointments
- Includes carer-specific support, recognising the wider care unit

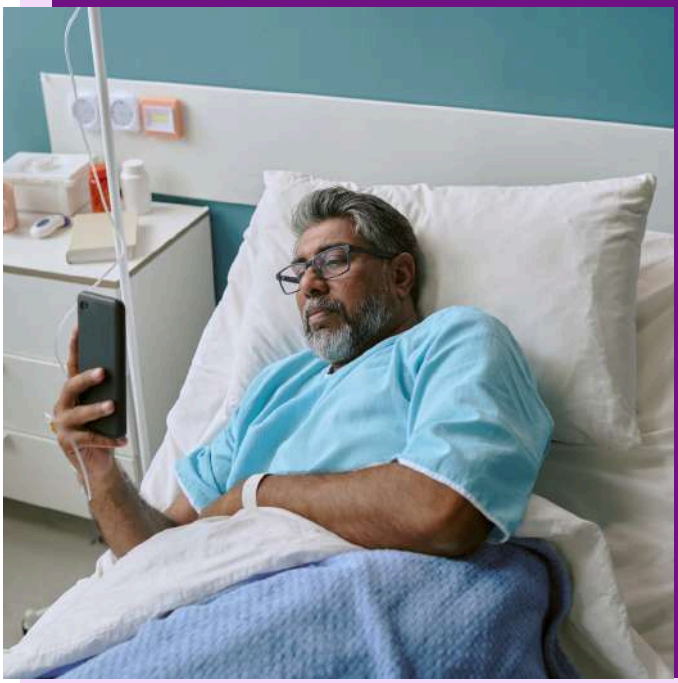
What digital support should not try to do

- Provide clinical decision making that replaces professional advice
- Overpromise reassurance, especially where symptoms may need urgent review
- Try to cover every cancer type and scenario perfectly from day one
- Use dense language or long, unstructured content

Think **“small, high impact support”**, built around real patient questions and service realities.

The misinformation problem, and why trusted content matters

When patients cannot get quick answers from trusted sources, many will search online. Some will land on excellent information. Others will land in a mess of myths, commercial agendas, or fear-inducing content. Between appointments is where this risk rises.



What the evidence says

- A study of popular cancer articles on social media found 1/3 contained misinformation and most misinformation had potential for harm
- A 2025 review in CA: A Cancer Journal for Clinicians discusses cancer misinformation on social media and its risks, reinforcing that misinformation is not fringe, it is pervasive and persuasive
- A 2025 report (UF Health, Journal of Cancer Education, reported via ecancer and UF news) found **93%** of patients with a new cancer diagnosis were exposed to at least one type of misinformation about cancer treatments

Even if you treat these figures cautiously due to setting and sampling differences, they underline a practical truth: **patients are exposed to misinformation at very high rates.**

What trusted content should look like in a patient app

- Written in plain English, short sections, scannable headings
- Clear “what to do next” steps
- Explicit signposting to NHS, charity and local service routes
- Gentle myth-busting where appropriate, without amplifying harmful claims
- Tailored content for common pathway moments, for example chemo side effects, radiotherapy fatigue, post-op recovery, results waiting

If you do one thing this quarter, do this: create a “Trusted Answers” library aligned to your service’s top recurring questions, and make it easier to access than Google.

Supporting emotional wellbeing between appointments

Emotional wellbeing support is not an optional extra in cancer care. It directly influences distress, coping, help-seeking, adherence, and how patients experience the pathway.



What the evidence says

- NCI guidance summarises evidence on anxiety and distress in cancer care, including meta-analytic figures for anxiety disorders in palliative care populations, reinforcing that clinically significant anxiety is common and must be addressed as part of care quality
- A Macmillan briefing reported that even 10 years after treatment, **54%** of cancer survivors still suffer from at least one psychological issue, highlighting how long emotional impacts can last

What emotional support can look like in a digital journey app

Keep it light, accessible and optional. Examples:

- Guided breathing for scans, results waiting, sleepless nights
- Short grounding exercises, for example 60 to 120 seconds
- Journaling prompts, for example “What do I need most today?”
- “What to expect” content that normalises common feelings without dismissing them
- Signposting to psychological support, counselling, Macmillan resources, local services
- Carer wellbeing prompts, because carers often carry silent stress

You are not trying to create a therapy product. You are creating **supportive scaffolding** that reduces isolation and gives people something useful to do with anxiety.

Symptom tracking and side-effect support that actually helps



Symptom tracking is one of the most practical digital features, but it only works if it is simple and tied to meaningful action.

What works well

- A small set of common symptoms aligned to the pathway, for example nausea, pain, fatigue, appetite, sleep, mood
- Trend views that help patients see patterns and triggers
- “When to seek help” guidance that is clear, safe, and aligned to local protocols
- The ability to note questions to ask at the next appointment
- A way to capture medication effects and side effects in plain language

What the evidence says about unmet needs and follow-up priorities

In the UK survey of post-treatment care, anxiety and fear of recurrence were among the most frequently addressed needs in follow up, signalling how common these concerns are.

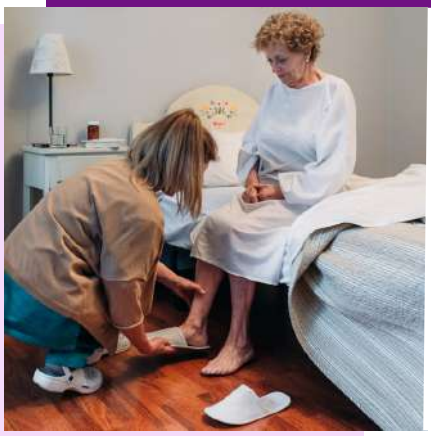
That matters because symptom tracking is not only about physical symptoms. It supports the wider “How am I doing?” question.

Common pitfalls

- Too many fields, making it feel like homework
- No clear guidance on what the data is for
- No reassurance or next step when symptoms are logged
- Unclear escalation routes

If you cannot integrate symptom tracking into clinical workflow initially, that is fine. Start with patient benefit: helping them describe issues accurately and feel more in control. Over time, you can add pathways for sharing summaries.

Carers: support the wider care unit, not only the patient



Carers are often navigating complex emotional and practical burdens, and they frequently feel invisible in the pathway. Yet they are critical to continuity and safety.

What the evidence says

- A Macmillan report found **61%** of people caring for someone with cancer experience some kind of impact on their lives as a result of caring, and very few receive a formal Carer's Assessment
- A 2025 paper on unmet needs reported that over **50%** of participants (patients and carers) received very little support in general, reinforcing that support gaps are common

What carers need in a digital support offer

- Clear guidance on common issues, what is normal, what needs escalation
- Practical support, managing fatigue, food, medication routines, transport
- Emotional support resources tailored to carers
- Permission and prompts to seek help for themselves
- Clear signposting to carer assessments, financial support, local and charity support

A simple but high-value digital feature is a "Carer space" that explains:

- What to look out for
- How to support someone through key moments
- How to look after themselves
- Who to contact and when

A simple framework for designing a digital patient journey

If your team is thinking, “Where do we start?”, start with the pathway and the moments that predictably generate uncertainty.



Step 1: Map the patient journey into phases

A practical set of phases could be:

1. Referral and diagnosis
2. Treatment planning
3. Treatment delivery
4. Recovery and follow-up
5. Living with and beyond cancer, or ongoing supportive care



Step 2: Identify “high anxiety moments”

Common moments include:

- Waiting for results
- First chemo, first radiotherapy session
- New or unexpected side effects
- Treatment changes
- End of treatment transition
- Fear of recurrence triggers



Step 3: Define what “good support” looks like at each moment

At each moment, define:

- The top 5 questions patients ask
- The top 3 fears patients express
- The top 3 actions you want them to take if concerned
- The trusted sources you want them to use



Step 4: Build content and tools around those moments

This is where a journey app shines. Instead of a generic library, you deliver:

- “What to expect this week”
- “Common side effects and what to do”
- “When to call us”
- “How to cope with results waiting”



Step 5: Close the loop with feedback

Include a lightweight way to ask:

- Was this helpful?
- What did not make sense?
- What do you wish you had known earlier?

That allows continuous improvement of content, and it demonstrates patient centred design in practice.



A useful design principle

Make the right thing easy. If patients have to hunt, they will default to Google. Given how widespread misinformation exposure is, that is a risk you can reduce with better design.

Getting started without adding burden

Many teams hesitate because they assume digital support requires a huge content programme, complex governance, and ongoing admin. You can start much smaller.



A realistic “start small” approach

Week 1 to 2: Define scope

- Choose one pathway segment to start with, for example chemo support
- List the top recurring questions and call drivers
- Agree safe, consistent wording and escalation guidance

Week 3 to 6: Build a minimum viable content set

- 15 to 25 FAQs
- A symptom tracking prototype for 5 to 8 symptoms
- Clear contact routes and “when to call” guidance
- A small wellbeing section, 3 to 5 tools

Week 7 to 12: Launch, learn, iterate

- Track usage and common searches
- Add content based on real questions
- Add carer resources
- Collect feedback and refine wording

How you justify value internally

Even without perfect measurement, you can link digital support to:

- Reducing avoidable distress, which is a quality outcome
- Supporting timely escalation, which improves safety
- Reducing repeated calls for basic information, which supports capacity
- Improving appointment readiness, which supports efficiency

You can also connect the conversation to missed appointment costs at system level, which are well evidenced in NHS data and literature.

Common objections, and how to address them



“We do not have time to maintain content.”
Start with a small set of high-frequency content and review monthly. In most services, a small subset of questions accounts for a large proportion of contacts.

“We are worried about governance and risk.”
Use trusted sources, keep language clear, and always include escalation guidance. Digital support should never tell someone not to seek care. It should help them decide when and how.

“Patients are not all digitally confident.”
Digital support should complement, not replace, existing routes. A simple, accessible design can improve equity, and carers often use digital tools even when patients struggle.

“We cannot tailor content to every cancer type.”
You do not need to. Start with content that applies across diagnoses, then add tailored pathways over time.

Want to continue the conversation?

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