South east London patient interface charter – co-design process.

The patient consensus statements were developed after rounds of engagement and consultation with staff and patients across south east London. There were 5 steps in the development process:

1. **User feedback surveys and conversations in clinical settings**
2. **Patient focus groups**
3. **Staff focus group**
4. **Hypothesis testing workshop (patients)**
5. **Staff and Patient joint workshop**

User feedback informed our understand the main problems patients experience when they move between services – from this feedback we generated a series of 'hypothesis statements' that summarised these key challenges for patients. The patient and staff focus groups refined the hypothesis statements and helped shape them into draft 'consensus statements' – setting out what patients should reasonably expect when transitioning between different clinical services. These statements were tested with patients at the hypothesis-testing workshop, after which the updated draft statements were finalised in a joint staff and patient workshop. The joint workshop was also used to bring together staff and patient views on shared behaviours at the interface: what do we owe to each other as individuals and how do we promise to try and act to ensure respect, trust, and clear communication.

This document summarises each stage of the development process and our understanding at that time. The hypothesis and consensus statements presented in the tables below reflect draft versions as they existed at each point in the process. The final table demonstrates how these themed draft statements were subsequently amalgamated to form the final patient charter.

Statement 1 – Prescribing and Medications

Delays or breakdowns in communication between GP practices and hospitals around medicines cause patient distress and cause blockages in getting the right care in a timely way.

Resonance	Experiences	Priorities
- Very strong resonance – multiple participants described this as a central issue. - '**blockages' – minimises the harmful impact – miscommunication causes HARM**	- Mother of participants discharged without essential drugs; district nurses not engaged; patient had to advocate and chase - 6 week struggle to access medication for wife due to bad hospital/GP communication – had to spend significant time calling. Had to make trip while on the call to go to hospital to get medication - Menopause medication delayed because GP didn't act on hospital discharge letter - Emergency case where if the participant hadn't thought to bring information about patient they would have died – hospitals couldn't access records overnight	**Very high priority – can have life threatening or otherwise harmful impacts**

Draft hypothesis statement after patient focus group

Delays or breakdowns in communication between GP practices and hospitals around medicines cause delays in getting the right care in a timely way, which can result in distress, confusion, and harm to the patient.

Staff Feedback Session

- Patients often face long waits for hospital pharmacy medication, and redirection to GPs or community pharmacies can cause week-long delays.
- Secondary care must clearly explain in letters why a prescription is needed so GPs can act safely.
- Communication about medicines is inconsistent; letters are often jargon-heavy, read by admin staff, and not always fit for purpose.
- System limitations (e.g., hospitals not using EPS) and reliance on GPs for non-prescribers add avoidable delays.
- Poor coordination between services leads to results being shared without explanation, causing distress and unnecessary follow-up.
- Clear, consistent, patient-friendly communication about results, medication plans and next steps is essential.
- Safe prescribing depends on timely, reliable information flow between primary and secondary care.

Proposed consensus statements after staff focus group:

- **Explain what's next:** tell me what will happen, when, and who is responsible for the next step
- **When things go wrong:** communicate openly, explain what happened, and tell me what will happen next.
- **Medicines clarity:** make sure I understand medicines are changed or added, how to obtain them and what monitoring is needed.
- **Support me while waiting:** give realistic timelines, escalation routes, and signposting to trusted support (including for carers).

Statement 2 – Inequalities: Co-morbidities

Patients with multiple conditions experience greater confusion and stress because services for different conditions aren't well coordinated, leading to less seamless care.

Resonance	Experiences	Priorities
- Strong agreement - Participants highlighted **pack of holistic approach** and conflicting advice between services – each service is focused on managing their condition and aren't conscious of how each treatment may impact ability to treat another – e.g. anti-depressants causing weight gain, fatigue reducing ability to exercise.	- Multiple patients resorted to carrying their own 'one pager' to avoid errors – example of this avoiding a mortality during an emergency incident - Confusion over letters and tests – unclear what test relates to what condition and **why** they are being asked to go to x place and have x test - Symptoms such as hypermobility overlooked despite being seen **in a complex conditions service**	HIGH

Draft hypothesis statement after staff focus group

Patients living with multiple conditions experience greater challenges in accessing the right care because services are poorly coordinated and condition-specific, advice on managing different conditions can conflict with each other, and it's unclear what tests and communications relate to which condition. This lack of holistic care increases stress and can worsen health outcomes.

Staff Feedback Session

- There is tension between specialist and generalist models; patients with multiple conditions benefit when generalists coordinate care with specialist input as needed.
- Some hyper-specialised staff may lack broader clinical experience, making whole-person care challenging; clinics run solely by specialist nurses may need more consultant support.
- Systems like EMIS provide safety prompts (e.g., contraindication alerts); there is uncertainty whether Epic offers equivalent functionality, and concern that clinicians must actively review full patient records.
- Teamworking is inconsistent - teams may understand holistic care conceptually but not always know individual patient context; robust induction and shared standards could help.
- Digital tools (e.g., Epic enhancements) may support better coordination but need exploration.
- Medication changes are not always well communicated; HCAs often relay messages, and patients may not recall or may not have been properly informed.
- Verbal information should always be backed up with written communication to support understanding.
- Multimorbidity creates anxiety because patients attend many appointments with different teams; without coordination, the burden sits with the patient.
- True holistic care is structurally limited - specialists can only advise in their field; generalists lack depth for all conditions.
- Past attempts at single points of contact did not progress beyond pilots; not feasible at scale.
- Shared care plans, clear roles, and coordinated information flow are realistic solutions.
- No single clinician should be expected to provide full cross-specialty advice; clarity and coordination matter more.

Proposed consensus statements:

- **See the whole me:** consider how tests and treatments interact across all my conditions.
- **Giving me tools and options:** support me with the knowledge, skills and confidence to manage my own condition

Statement 3 – Inequalities – Literacy, Digital		
Patients with lower literacy or digital literacy are more likely to rely on others to support them and/or manage their care and may struggle to access or understand written, verbal and digital communications.		
Resonance	**Experiences**	**Priorities**
- Agreement, but participants expanded scope: **language barriers, hearing loss, and physical disabilities** also impact communication. - Digital systems (e-consult, NHS app) create barriers for some.	- Mother's dentures and hearing aids not treated as medical devices; caused severe communication issues. - Struggled with e-consult; led to A&E visits. - People with mental health or disabilities need more time and flexibility.	Medium to high – critical for equity
Draft hypothesis statement after staff focus group *Patients with lower literacy, digital literacy, language barriers or sensory and processing impairments often struggle to access or understand communications, reducing self-empowerment and risking poorer health outcomes.*		
Staff Feedback Session		
- Having good quality letters may go some way to helping this situation – most people have at least someone they are able to go to for help interpreting communications. - We are moving towards a digital first way of communicating, but don't do enough to make sure those who don't understand do not get left behind. - Patient records theoretically should include information on preferred communication style – how can we make sure this is honoured wherever possible? - There are ways to code in primary care around accessibility requirements with SNOMED codes, but this isn't consistent and there are challenges.		
Proposed consensus statement **Work together:** understand that navigating care can cause confusion, stress and uncertainty; I may need additional help or to be communicated with in a different way.		

Statement 4 - Communication		
Patients value communications that are clear, consistent, and timely more than the type of communication used (e.g., letter, text, email).		
Resonance	**Experiences**	**Priorities**
- Mixed views. - Most agreed clarity and timeliness matter most, but **two-way communication** and	- Criticized one-way communication; needs ability to respond. - Anxiety triggered by late-night "results available" messages without context.	Medium-high

choice of channel are also critical. - Notifications without actual information cause anxiety.	- Text limits and wording matter; some prefer phone calls.	

Draft hypothesis statement after staff focus group

Patients value clear, timely and two-way communication above all. While consistency is important, communication should also allow interaction and respect patient preferences for channel where possible.

Staff Feedback Session

- PCARP priorities focus on this topic
- More channels available nowadays but can create more challenges and be more confusing.
- PIFU should provide contact details – not always functioning phone numbers/ emails
- Conversations about adding contact emails to the top of e.g. discharge letters, patient communications. Not done and even when done no guarantee of the emails being responded to/ phone picked up.
- MyChart theoretically has some functionality to support two way communication, but not routinely monitored.
- GP have Accurx and NHSapp (increasingly) but not clear whether MyChart can/ does get used in this way.

Proposed consensus statements:

- **Plain, timely, two way**: communicate clearly, within the timelines I have been told to expect, and give me a way to ask questions. Take my preferred method of communication (phone, email, text) into account where possible.
- **Paper trail**: all communications relating to decisions, changes, and escalations in my care are written in a way I can understand are easy to access.

Statement 5 – Carers and Communication

Carers and family members play a critical role in managing patient care and communications, but often feel unsupported and overwhelmed by the system.

Resonance	Experiences	Priorities
- Very strong agreement. - Carers described as “essential glue” holding care together, but often treated as nuisances. - Carers sometimes have their own care requirements	- Advocated for mother; described lone elderly patients as extremely vulnerable. - Felt dismissed when asking questions. - Carers save the system time and money but aren’t recognized.	HIGH – vital for patient safety

Draft hypothesis statement after staff focus group

Carers and family members are essential in coordinating care, advocating for patients, and managing the day to day care and safety of the caree. However, they often feel unsupported by the system or otherwise excluded. This lack of recognition and forced advocacy for vulnerable patients increases stress and risk for patients and the carer, particularly when the carer themselves has their own care requirements.

Staff Feedback Session

What was discussed

- Carers sometimes speak on behalf of patients, especially in emotionally charged contexts such as frailty, serious illness, or end-of-life care.

- This can lead to situations where conversations are shut down or shaped by the carer's preferences rather than the patient's.
- Emotional burden influences behaviour.
- Participants described how grief, anticipatory grief, and distress can cause carers to revisit concerns repeatedly, sometimes prolonging complaints or seeking reassurance in cycles.
- Balancing objectivity and subjectivity is difficult.
- Carers act with good intentions, but their perspective can diverge from what the patient might choose.
- Clinicians face limits: even with training, some conversations remain inherently difficult because of the emotional complexity and the structural constraints of the situation.
- Guidance cannot "solve" this, but **principles can support better communication**, help maintain patient voice, and acknowledge carers' emotional needs.
- Important to recognise boundaries: clinicians can empathise but can't provide unlimited emotional support or allow complaints processes to become open-ended counselling.

Proposed consensus statements:
Include my carer (with consent): recognise and support my carer or named person as a partner in safety and communication.

Statement 6 – Clear Point of Contact

Patients feel more confident and less anxious when they know who they can contact for more information about their care and their progress (e.g., when they may expect to be contacted), especially when managing multiple health conditions.

Resonance	Experiences	Priorities
- Strong agreement - Lack of clear point of contact forces patient to advocate for themselves or seek private care	- Cancer care improved because of clear nurse contact; contrasted with past confusion. - Nine-month wait for menopause referral; didn't know who to contact. - Specialist conditions have better contact points; general conditions do not.	HIGH – reducing anxiety and improving outcomes

Draft hypothesis statement after staff focus group
Patients feel safer and less anxious when they have a clear, reliable point of contact for questions and are updated, especially during long waits, when managing multiple conditions, and when moving through 'less specialist' condition pathways.

Staff Feedback Session

What was discussed

- This is a widely recognised need and has come up often in patient feedback.
- Patients can feel lost in the system, especially across multiple services or pathways.
- Digital access to test results (e.g. through patient portals) provides transparency but also anxiety: Results arrive quickly, often with no explanation. "Abnormal" findings appear without context, leading some patients to assume the worst. This is relatively new that patients are this well informed so quickly, and therefore more of an issue than it was a few years ago
- Variation across services in how clearly and accessibly they communicate results (some use plain language, others don't).
- Escalation routes are unclear.

- While mechanisms like PALs services exist, these shouldn't be the default entry point. - Ideally patients would have a named contact or at least a direct route to the relevant team. **Feasibility discussion** - A single universal point of contact for every patient is likely not feasible. - A minimum expectation -that patients know who to contact and how -feels achievable and could be included in the consensus. - Participants favoured simple principles, not lengthy, overly technical guidance.
Proposed consensus statements: **A reliable route in:** provide a contact in a department or team so I know who to reach throughout my pathway.

Staff and patient workshop – refining the consensus statements

Statement	Discussion	Inclusion in Final Statement(s)
1. **See the whole me:** consider how tests and treatments interact across all my conditions.	- Strong agreement that patients want to be seen as whole individuals, especially when living with multiple conditions. - Desire for clinicians to understand how tests, treatments and advice interact. - Avoid duplication and ensure all appointments and letters have a clear purpose.	Final Statement 1 (Whole-person, joined-up care)
2. **Work together:** understand that navigating care can cause confusion, stress and uncertainty; I may need additional help or to be communicated with in a different way.	- Navigating care is stressful; communication needs differ between people. - Clinicians should consider other services the patient interacts with, and involve carers where appropriate.	Final Statement 3 (Working together, adapting to needs, involving carers) Some elements also support Final Statement 2 (explaining transitions)
3. **Explain what's next:** tell me what will happen, when, and who is responsible for the next step.	- Clear, proactive communication about what will happen, when, why, and who is responsible. - Seen as essential for safe transitions.	Final Statement 2 (What happens next, why, who is responsible, when to expect contact)
4. **Plain, timely, two way:** communicate clearly, within the timelines I have been told to expect, and give me a way to ask questions. Take my preferred method of	- Communication must be clear, compassionate, and free from jargon. - Use preferred communication methods where possible. - Provide ways to ask questions.	Final Statement 6 (Clear, timely, plain language communication) Some elements absorbed into Final Statement 4

communication (phone, email, text) into account where possible.	- Acknowledge that some jargon is unavoidable but should be explained.	(understanding results and medicines)
5. Paper trail: all communications relating to decisions, changes, and escalations in my care are written in a way I can understand are easy to access.	- "Paper trail" outdated -must include digital forms. - People need accessible, understandable written records. - Communication should be personalised but manageable. - Important that written information explains context and purpose. - Must reflect different digital access needs.	Final Statement 1 (whole-person care, clarity of purpose)
6. Close the loop on tests: tell me when and how results will arrive and who will explain them.	- Results must always be delivered - "no news is good news" unacceptable. - People need to know what format they will receive (summary vs full report). - Should include where results will be found. - Important for safety and for avoiding missed follow-up. - Should be clear who to contact if concerned.	Final Statement 4 (results and medicines clarity) Elements also feed into Final Statement 5 (support while waiting)
7. A reliable route in: provide a contact in a department or team so I know who to reach throughout my pathway.	- People want to speak to a human; it is reassuring. - "Route in" phrasing confusing - sounds like access to the service itself. - Providing personalised contacts is unrealistic for all pathways. - **Other communication improvements may make a standalone statement unnecessary.**	Incorporated into Final Statement 2 (who is responsible) and Final Statement 5 (who to contact) Not included as a standalone final statement.
8. Shared purpose in referrals and discharge: when my care is being transferred (for example from the hospital to the GP) I am told why this is happening and what to expect.	- Term "shared purpose" seen as unclear. - Participants preferred: involvement, clear transfer of care, explanation of what's happening. - People need to know what to expect when care moves between services.	Final Statement 2 (what happens next during transitions)
9. Support me while waiting: give realistic timelines, escalation routes, and signposting to trusted support (including for carers).	- Change "escalation routes" to "what to do if my condition worsens." - Important to distinguish types of waiting (for specialist, for next step, for results). - Need to involve carers.	Final Statement 5 (support while waiting, self-management, condition changes)

	- People want reassurance they are not forgotten.	
10. **Medicines clarity:** make sure I understand medicines are changed or added, how to obtain them and what monitoring is needed.	- Language needs simplifying ("monitoring", "obtain medicines"). - People like the structure "when, why, what, which." - Include entitlement to medication review. - Useful in discharge scenarios.	Final Statement 4 (medicines understanding) Parts also support Final Statement 5 (post-discharge medication clarity)
11. **Include my carer (with consent):** recognise and support my carer or named person as a partner in safety and communication.	- Carers are vital for communication and safety. - Patients need ability to update who they trust and want involved. - Should recognise both informal and formal carers.	Final Statement 3 (working together and involving carers) Some consideration also fed into Final Statement 5 (carers during waiting)
12. **Giving me tools and options:** support me with the knowledge, skills and confidence to manage my own condition	- Should emphasise practical tools (e.g., using inhalers correctly). - Especially important during waiting or post-discharge. - People need clear signposting to reliable resources.	Final Statement 5 (practical support while waiting). Supports Final Statement 4 (understanding care plans)
13. **When things go wrong:** communicate openly, explain what happened, and tell me what will happen next.	- Important but may not need a standalone statement. - Should link to communication expectations and transparency. - "Whose job is it?" noted - need clarity.	Final Statement 6 (clear communication including when delays/mistakes occur)

Staff and patient workshop – developing 'shared behaviour' statements

During the joint workshop, staff and patients worked together to suggest and agree a series of 'shared behaviour' statements. The aim of these statements was to set out what staff and patients promise to each other to promote good communication, mutual respect, and trust when patients move between clinical services.

Each workshop participant was given the opportunity to write down many ideas for statements, after which the group reviewed, challenged, evolved and finally prioritised.

We carefully considered the language used to describe these statements, appreciating that terms such as 'responsibility' and 'behaviour' carry different interpretations for different people. We also recognise that not every patient has the

confidence, knowledge or support to advocate for themselves when navigating the health and care system. On balance, we decided that the term ‘responsibility’ was most appropriate as ‘behaviour’ implies an expectation of action was, which is not the case. At it’s core, this charter is intended to help patients understand what they should reasonably expect, particularly at times of uncertainty, when they experience delays or challenges, or when they feel less able to speak up for themselves, rather than set expectations of what actions a patient is expected to take in certain scenarios.

The final statements were agreed by both staff and patients to be the highest priority, most relevant and feasible-to-deliver statements. Staff members comprised administrators, primary and secondary care clinicians, as well as system stakeholders), representing consensus across clinical environments in the interface.