Patient-held Continuity Pack: 15-minute talk

Facilitator copy. Bring a blank folder, dividers, current-information sheet and appointment sheet. About 1,400 spoken words plus demonstration and quiet writing time. Use the clock cues to keep the session to 15 minutes; allow discussion afterwards. Everything in the demonstration is fictional. Do not invite personal medical stories in the room.

00:00 to 02:00 | What this is for

“This is a folder kit for keeping your own healthcare notes and copies together. Its name is the Patient-held Continuity Pack. The idea is modest: make it easier to bring the information and questions you want to an appointment, and to leave with a clearer note of what happens next.

“A person can have letters in one place, questions in another, and something they meant to ask still in their head. After a visit, there may be an expected letter, another appointment or a test result to keep track of. That can be a lot to organise, especially when someone is unwell or already managing many other things.

“The pack is optional. You do not have to be good at paperwork. You do not have to fill every box. Someone you trust can help, if you want them to. A service still has its own responsibilities for records and coordination. Having a folder must never become a condition of receiving care.

“Today I will show what is in it, how to begin without sorting your entire history, and what we would like people to test. Please keep any example you use here fictional. We want feedback about the design, not your health records.”

02:00 to 04:00 | What supports the idea, and what we do not know

“The HSE already advises people to prepare questions, bring medicines information, make notes and check the next steps at appointments. It also provides My Medicines List. This pack puts space for those everyday activities into a simple folder structure.

“That does not mean the HSE has approved this pack. It has not. It also does not mean this particular layout has been shown to reduce errors, improve treatment or save money. We have not tested those claims and are not making them.

“The first question is more practical: can people understand this sheet and use the parts they find helpful? Does it make an appointment easier to prepare for, or does it just add another form? Are the words clear? Is there enough space? Could any prompt be misunderstood?

“It is a patient support tool, not a clinical system. It is not the official record and it cannot tell whether a letter is correct or a medicines list is current. If you already have a care passport, a current pharmacy list or another system that works, keep using it. The folder can hold those existing documents. It should not make you copy everything again.”

04:00 to 06:00 | Start midstream

“The starting point is today. Put together any folder. The dividers are there if they help: current information, appointments, letters and care plans, tests and results, waiting and follow-up, and older information.

“Put the current-information sheet at the front. Add what you know and the date. Leave something blank or write ‘not sure’ if it needs checking. Keep a current medicines list beside it, with its own date. The blank medicines worksheet is optional; a list you already use can go there instead.

“Then put a blank appointment sheet in the folder and use it at your next visit. That is enough to begin. You do not need to reconstruct years of care first. Old letters can be added gradually, newest first in each section.

“When information changes, date the update and note its source. Keep original letters intact. Mark an old summary as superseded and move it to the older section, so it does not look current. If two sources disagree, turn that into a question for the relevant service. Do not guess which one is right.”

[Show the six dividers and place current information and a blank appointment sheet at the front. Keep the demonstration within this two-minute slot.]

06:00 to 08:00 | Before and during one appointment

“Let us use a fictional example with no medical detail. Someone has a visit coming up. Their main question is when the next appointment should happen. They are also waiting for a letter and do not know where it will arrive.

“At the top of the sheet they add the visit details. Under ‘what matters most’, they write the appointment-date question. Under the other questions, they write: how will I receive the letter, and who should I contact if it does not arrive?

“During the visit, the middle of the sheet is for their understanding of the conversation. It is fine to use rough notes. If writing makes it harder to listen, a supporter can help with permission, or they can make notes just afterwards.

“There is no prize for a complete page. One useful question and one clear next step can be enough. If the answer is uncertain, write that. If something needs checking, leave it as a question. Do not turn an uncertain memory into a fact just to fill a box.”

[Point to the relevant boxes. Give the room 30 seconds to write one entirely fictional question, or think of one without writing. Do not collect the sheets.]

08:00 to 10:00 | Checking understanding is not sign-off

“The sentence at the centre of the pack is: ‘Can I read back what I understood and check whether I have missed anything?’

“That asks for help understanding this conversation. It is not asking a clinician to sign a document, certify a history, endorse this project or approve the whole folder. There is deliberately no clinician-signature box.

“In our fictional example, the person might say: ‘I understood that your office will arrange the next visit and that I should contact the office if I have not heard by the date we discussed. Have I got that right?’ If the answer corrects their understanding, they change the note. If it cannot be resolved there, they write down the contact route for clarification.

“For tests and results, ask who reviews the result, how you will receive it, and whom to contact if it has not arrived by the agreed time. The folder does not check results or send reminders to a service. Silence should not be treated as proof that a result is normal.

“Also ask what changes would mean you should seek help sooner and how to get that help. The sheet gives space to record that advice. It does not supply the advice itself.”

10:00 to 12:00 | Keeping it safe and private

“The templates are blank files. The first release has no patient account, upload form or health-record database. When you fill them in, the information stays in your folder or wherever you choose to save it. The project does not need a copy.

“Choose what to share at a visit. Keep contact details inside the folder and keep the folder somewhere private. Check shared printers before leaving. If you edit a Word document, check whether your editor saves to a cloud account; choose a local folder if that is what you want.

“Please do not send completed sheets to us or put them in a public comment. Design feedback does not need a diagnosis, a name or a copy of a letter. A blank or made-up example is enough.

“Do not start, stop or change treatment because of a template or an uncertain note. Ask your clinician or pharmacist about unclear instructions. And do not wait for paperwork when you need care. These boundaries belong in the design, not just in a disclaimer that nobody reads.”

12:00 to 14:00 | A small first test

“The proposed pilot is small: five to eight adults, over two to four weeks. First, people would try a fictional example. If they wanted, they could also use the folder at a routine appointment. There is no need to arrange a medical visit for the pilot.

“We would ask what they found, what they skipped, where they got stuck, and whether they understood the limits. Participants would keep their completed folders. Feedback would avoid personal health details. Taking part would be optional, and stopping would not affect care.

“If someone thinks a clinician must sign the sheet, or that it verifies a record or tells them to change treatment, that is a reason to stop and fix the wording. It is not a reason to blame the user.

“A useful report would include difficulties, non-use and withdrawals as well as positive comments. Even if everyone liked it, that would still not be evidence of improved clinical outcomes.”

[Allow 30 seconds of quiet review. Invite people to identify a word or box that could be confusing, without sharing a health story.]

14:00 to 15:00 | The request

“The pack is free to download, print and adapt under an open licence. The PDFs, editable files, source and guidance are at continuity.stationarystore.ie. The release number is on each template so changes can be tracked.

“What I am asking for first is a review of the blank sheet. Is it useful? Is it readable? Could it add pressure or confusion? What should be removed or changed before a wider pilot?

“There is a one-page brief you can take away. Please send written design feedback without personal health information. No organisation is being described as a partner or endorser. If people want to explore a pilot, we can agree that separately using the proposed plan.

“You can also just use the folder for yourself. Put today's information at the front, take one sheet to the next visit, and add the past when you have time.”

[Finish at 15:00. Discussion, if offered by the host, follows outside the timed talk.]