Royal College of Physicians | Health Informatics Unit

Personal health record (PHR)
User insights
Jo's journey

Introduction

NHS England commissioned the Royal College of Physicians (RCP) Health Informatics Unit (HIU) to undertake a study to better understand the needs of service users in relation to personal health records (PHRs) and the implications for providers, clinicians and commissioners.

This is one of six documents that explore findings from the study in the form of user journeys.

The user journeys have been created for those who commission, develop and implement PHRs. They are intended to present the issues raised in the user insights project from the perspective of the patient and in an easy-to-digest format. It is hoped that the user journeys will help to demonstrate the opportunities that PHRs present and to aid understanding of the needs of those who are using them.

Each user journey is presented in three formats: a narrative (that highlights key points), a matrix and an audio recording that can be found via the RCP HIU webpages. These formats complement each other and it is advised that they are reviewed together.

Each user journey draws out the user's thoughts, feelings, actions and needs along their PHR journey. Each journey focuses on a different type of condition and situation. It is important to note that the learning points from each journey often apply across all PHR users.

- Jo's journey explores her insights from using a PHR in her mental health recovery journey.

- Josh and Michelle's journey explores their insights from a PHR that supports Josh, who is a young boy with complex needs.

- Frank's journey explores his insights from using a hospital PHR to manage and maintain his health after he finished treatment for prostate cancer.

- Tim's journey explores the insights on a PHR of someone who has high blood pressure but does not experience symptoms and considers himself to be very healthy.

- Brenda's journey explores her experience when her PHR was not meeting her expectations or needs.

- Sugra's journey explores her insights from using her PHR to manage her condition following her diagnosis.

The user journeys are based on a constructed patient telling their story. They are amalgamated from patient records or existing PHRs. The journeys have been created from analysis of nine focus groups and 21 interviews with PHR users, former users and non-users, to illustrate their thoughts, experiences and needs; and six interviews with clinicians and social care professionals. The user journeys are grounded in the data.

The user journeys are not a summary of the full findings: the full findings, published in 2017, can be found on the RCP HIU webpages.

Jo's journey – summary

Jo is an inpatient at a psychiatric hospital; she was admitted after she attempted suicide 3 months ago. At discharge, she is offered a support package that includes access to a community mental health support group that meets weekly, a care coordinator called Gary, counselling and access to a PHR, which she calls 'the app'. She is also prescribed an antidepressant.

- Jo found her PHR to be an effective tool to support her throughout her recovery journey.

- Jo felt that her PHR supported her to develop self-reflection skills. She recorded her moods, weight and blood pressure (BP) weekly at a support group at first. As Jo recovered, at home she recorded daily her mood, alcohol intake and exercise. Reviewing the information led Jo to develop greater self-awareness.

- Jo felt that the PHR helped her to identify and monitor her triggers for emotional distress, psychiatric symptoms and unhelpful health behaviours. For example, by recording her alcohol intake and mood every day and comparing the monthly charts that show the results, Jo could see that she felt low when she had had a few 'heavy nights'. She would therefore know to cut back on alcohol.

- Jo felt that her PHR gave her the tools and evidence she needed to be heard by health professionals and to influence her care. She took her mood charts and weight chart to her GP to ask for a change in medication.

- Jo's engagement with and use of the PHR was hampered when some of her care team were not engaged or supportive of her PHR. Her care coordinator did not upload her care plan or engage with the PHR.

- When Jo was unwell, she wanted someone (a professional or family member) to monitor her PHR and leave messages to encourage her.

- Jo needed intensive face-to-face support for the first weeks/months that she was using the PHR, especially because she was experiencing a condition where low motivation is a symptom.

- Jo's needs changed over time. Her motivation to continue to use the PHR was based on her new needs being met, so the functions of the PHR that she used and the frequency of her use also varied. The frequency of her use of the PHR was not a reflection of her satisfaction with it.

Jo's journey – full story

Introduction to the PHR and initial thoughts

Jo is introduced to the PHR by a psychiatric nurse who explains to her that it could help her to monitor how she is feeling and her BP; that she could get access to her care plan on it; and that this could help her to get better.

- Jo feels a bit anxious and a bit scared about the future.

- She feels sad and uncertain, and she experiences bad days and better days.

- Jo feels motivated to get better but she thinks that her recovery will be hard.

- Her motivation to undertake daily tasks is low.

- She often feels tired and can feel confused, and she is focusing on one day at a time.

- Jo thinks that the PHR could be a good thing and she is willing to try it, but she does not think that she will get her head around it until she starts using it.

- She feels happy to be directed by her health professionals as to what will help her get better.

- Jo's trust in healthcare professionals is high.

Preparation for adopting the PHR – period from decision to adopt the PHR until the first login

Jo visits her weekly support group (facilitated by Barbara) for the first time. She is warmly welcomed and spends some time chatting to another service user. Barbara takes the group through how to use the 'app'. Barbara shows the group how simple it is to log in and what the different functions are. She tells the group that when they attend their weekly support group meeting she will offer to take BP readings and weight measurements, and help to enter the data into the app. She also tells service user that if they do not have a laptop at home, she will arrange for one to be provided to them.

- Jo feels a bit nervous before attending the group but is reassured by her time with the other service users and by Barbara.

- She feels glad to hear about the ongoing support with using the app that Barbara will offer.

- Jo feels even more motivated to use the app when she is offered a free laptop.

- She feels that she will need support from Barbara to be able to use the app.

Adoption – period covering the first 4 weeks of use

Jo looks forward to attending her support group the following week. On the day that the group meets, she is very tired because she has had a bad night and she woke up with a low mood. She considers not attending the group, but she decides that it would be good for her to be with others. She attends the group.

At the group, Barbara helps Jo to set up her app. Jo is curious to see her care plan. Barbara takes Jo though the login and encourages her to complete a mood questionnaire straightaway. The results show a 'sad face'. Jo has her BP and weight measured and, together with Barbara, she enters the data into the app.

Jo asks Barbara to show her the care plan on the app and is disappointed to see that her care coordinator, Gary, has not added it. Barbara encourages Jo to use the app at home and offers to help her to review the contents at a group meeting.

When Jo is at home and alone, she is less motivated to use her app. It is a hassle to set up the laptop and, anyway, she cannot get access to her care plan. It is different when she is in the group because if anyone gets stuck they help each other out. Really, the most important part of the whole thing is the support group. She uses her app once a week.

- Jo feels low motivation to undertake lots of day-to-day activities.

- She feels that the contact with the support group is a real help.

- Jo feels that the encouragement from Barbara and the group helps her to use the app.

- She feels frustrated that her care plan is not on the app and she cannot understand why it is not there.

Using a PHR as a tool for self-reflection

Jo's mood stabilises a bit and some days she feels that she has a bit more energy, although she has good days and bad days. She has been attending the support group for a number of weeks and she still looks forward to the sessions.

Now when Jo logs in to her app at the support group, she can track her BP, weight and mood over the previous weeks. She can see that her weight has crept up a little and so has her mood, although there was a dip in her mood 2 weeks ago. Jo is interested in managing her weight and finding out whether there is something she is doing that contributes to her low mood. Jo is more confident using the app and she starts to use it daily at home to monitor her exercise, alcohol intake and mood.

After a few weeks, Jo's mood starts to get low again. She completes the mood questionnaire and for the fifth day in a row she sees a red 'sad face'.

Jo wonders what the point of doing this is. She knows that she feels rubbish; she does not need a row of sad faces to tell her that. In fact, Jo thinks that they might make her feel worse. No one else is looking at the app, not her care coordinator or a friend or family member. Her care coordinator still has not uploaded her care plan. Jo thinks that she would really benefit from someone, not necessarily a professional, checking the app every now and then, or being alerted when she is feeling bad. She thinks that she might stop using the app.

Jo goes back to the support group the following Monday and talks to Barbara. Barbara says some things that Jo thinks are very helpful and she wishes that Barbara or someone else would put key messages or quotes on the app that she could see when she logged in and was feeling bad. Jo feels that she would take the messages more seriously if they came from someone other than herself. Jo takes some time during the support group to review the app. She realises that she had had a couple of heavy nights of drinking just before her mood dipped and she decides to monitor this in the future.

Over the coming months, Jo continues on her recovery journey. She visits the support group less frequently. She continues to use the app almost daily and she reviews her results at the end of each week. Through this use, she has been able to identify when she feels that she needs to drink less alcohol, exercise more or contact a family member or professional for extra support. She has started to add inspirational quotes, which she feels help her to keep doing what she should be doing.

- Jo feels more motivation to undertake day-to-day activities.

- She feels pleased with the work that she has done to identify things that she can do to help her feel better.

- Jo feels that she is making progress on her recovery journey.

- She continues to feel frustrated that her care plan is not on the app and she cannot understand why it is not there.

- Jo thinks that the app could be more than just a monitoring tool: it could have a place for quotes and messages.

Using the PHR as a tool to advocate for a change in care and to communicate with those who are outside the care profession

Jo continues to be concerned about her weight; she can see from her app that it has increased since her medication changed. She looks up her medication on Google and sees that one of its side effects is weight gain. Jo wants to talk to her GP about this but she is afraid that she will not be taken seriously; she knows that the GP does not have a lot of time with her. Before going to the GP, Jo prints her weight charts and her mood charts. These show a stabilising of her mood and an increase in her weight. Just before her appointment, Jo feels nervous but prepared.

Jo is really pleased with her GP's response to her. Jo feels that she really clearly communicates her concern about her medication and presents the evidence to back it up. Jo feels like an equal partner in the conversation when the GP thanks her for her preparation and they discuss alternative medications. Jo is happy to explain the app and the role it plays in helping her to stay well. She is pleased when, after describing her frustration that her care plan is not on the app, the GP calls her care coordinator and the care plan is uploaded. Jo feels in control of her interactions with her GP.

Over time, as Jo's recovery journey continues, the app is developed to incorporate multimedia and her use of the app changes. Jo no longer uses the app daily to complete a mood diary, because her mood has improved and is stable. She now uses it as a way to record and store information such as quotes, likes, dislikes and YouTube videos that keep her well. She logs in to the app when she is having a bad day, to remind herself about her wellbeing plan. She no longer wants anyone else to access the app: it is her app for her use. She may choose to share bits of it with other people for specific reasons; for example, she shares a section of her wellbeing plan with her employer, so that he better understands how to support her at work.

- Jo feels empowered.

- She feels that she owns her app.

- Jo feels that the app is there for her when she needs it.

Jo's journey matrix

Jo, aged 43, is an inpatient at a psychiatric hospital; she was admitted after she attempted suicide 3 months ago. At discharge, she is offered a support package that includes access to a community mental health support group that meets weekly, a care coordinator called Gary, counselling and access to a personal health record (PHR), which she calls 'the app'. She is also prescribed an antidepressant. Jo is unemployed at the time of her discharge.

	1. Introduction to the PHR (day 1)	2. Preparation for adoption (week 1)	3. Adoption and early use (weeks 2 to 5)	4. The PHR as a tool for self-reflection (week 5 to year 3)	5. Using the PHR to aid advocacy and maintain wellbeing (years 3 to 15)
Doing	• Leaves psychiatric unit • Moves back into her flat • Taking medication • Shopping and cleaning • Sees her care coordinator	• Stays in her flat a lot • Attends a weekly support group • Logs on to the app • Watches how the BP and weight functions work	• Attends doctor's appointment and counselling • Visits family and friends • Attends weekly support group • Logs on to the app • Is shown how the BP and weight functions work	• Attends a weekly support group • Completes a mood questionnaire, and record of exercise and alcohol at home • Completes BP and weight charts at the weekly session • Reviews data at the weekly session • Starts an exercise group	• Continues to monitor health and manage health behaviours • Attends GP appointments • Volunteers at a charity • Uploads videos and quotes to keep well • Shares a page with her employer
Thinking	'I want to get better.' 'I can't see how to get better.' 'The doctors know what is best for me.' 'The app could be a good thing.'	'It looks simple enough to use.' 'I won't remember how to use it.' 'I couldn't do this on my own.' 'I need support.'	'Mood questionnaire makes me think about how I am feeling today.' 'I won't be able to do this at home every day.' 'Good to see my BP and weight.' 'Why isn't my care plan on the app? Does Gary not care about the app? I need to be supported.'	'I am working hard to get better.' 'I can see that on weeks that I drink lots I feel worse, so I take a break from wine for a while.' 'When I have low mood and I see the mood diary has a red sad face it tells me nothing: I know I feel bad. Why doesn't it tell me something to help me feel better?' 'I wish someone else could see how I am feeling.'	'I want to change my medication, I've put on weight. The doctor won't take me seriously.' 'The doctor listened when he saw the data on my app.' 'I no longer want people to be able to log in to my PHR. I do show someone bits of it, but only if it helps them to know what I need. No one can log in.' 'My PHR is part of what keeps me well. It is mine and for me.'
Feeling	*Anxious* *Sad and uncertain* *Motivated to get better* *Sometimes tired and confused* *Surviving day to day*	*Mostly feels the same as she has since discharge* *Nervous before the first session* *Glad of ongoing support with the PHR* *Motivated to use the PHR when she is given a laptop*	*Feels better than she used to but her mood is still up and down* *Low on the day of the group session and glad of support and encouragement from the group leader and other members* *Frustrated that the care plan isn't uploaded, and annoyed with Gary, the care coordinator, for not uploading the care plan*	*Moods up and down* *Pleased to have identified triggers and to be learning what can keep her well* *More in control* *Sometimes alone* *Still frustrated that the care plan isn't uploaded*	*Most days she feels like the future will be better and that she can cope with day-to-day activities* *Before her GP appointment, she is nervous but prepared* *After the GP appointment, she is proud and more in control of own health and healthcare* *Able to advocate for change in treatment*
Pattern of PHR use	Not applicable	Once	Weekly at sessions	Daily at home, and review at weekly sessions	It varies: between five times a week and five times a month, depending on how she's feeling
Satisfaction with the PHR	High	High	Low	Medium	High
User's needs for the PHR	• Encouragement to adopt it, but not pressure • Face-to-face introduction to the PHR • Clear, realistic information about the PHR that is easily digestible • Reassurance that the PHR does not replace face-to-face support and the support group will be ongoing	• Ongoing encouragement to use the PHR • Face-to-face support • Laptop	• Support of the wider care team, including the care coordinator • Care plan uploaded to the PHR • Communicate the realistic capabilities of the PHR: what it is designed to do • Ongoing support • Recording health behaviours and symptoms	• Tracking health behaviours and symptoms over time • Positive messages from others on the PHR for when she's feeling low • Someone else, a professional or a friend, to access the PHR when she's feeling down	• A PHR that works on a smart phone • Multimedia capability to add own resources to help to maintain wellbeing • Control over who has access to the PHR, including which professionals

Please note that the user journeys are based on a constructed patient telling their story. They are an amalgam of real patients or existing PHRs. The journeys have been created from analysis of nine focus groups and 27 interviews with PHR users, former users and non-users to illustrate their thoughts, experiences and needs. The user journeys are grounded in qualitative data.