

# Oncology Remote Monitoring at Home

## Focus Group Feedback Report Dec 2022

### Summary

This report relates to the Oncology Remote Monitoring at Home (OM@H) pilot project currently being undertaken by Dorset Cancer Centre at University Hospitals Dorset NHS Foundation Trust (UHD), working in partnership with Dorset Integrated Care Board and Dorset Healthcare University NHS Foundation Trust, to enable the remote monitoring of oncology patients who are undergoing cancer treatment (Radiotherapy, Chemotherapy or Immunotherapy) using an Oncology remote monitoring system.

The report details the findings of 3 focus groups undertaken by Involving People, with OM@H project team members, to gather feedback on aspects of the service to help and support service development. (see “Oncology Remote Monitoring at Home, Proposal to Undertake Focus Groups, Nov 2022” for more detail).

The main themes arising from the discussions were:

- Information provided to patients, whether training guides, information leaflets etc needs to be clear, unambiguous, and appropriate, where possible, for people with additional communications needs.
- Ensure patients are clear that “training” is available for care givers and families if the patient wishes and agrees.
- The “hotline” number and the “helpline” number need to be explicit in what they cover and what they don’t.
- It needs to be clear for patients that the “hotline” is the same number they may have been given for other clinics (cancer related) or if they have been given “hotline” numbers for other non-cancer conditions, how they relate to each other/when they should be used etc.
- It needs to be explicit that the system is not monitored real time 24/7, even though the system and information state this, staff must be assured that the users have acknowledged and understood.

## **Methodology**

See proposal document for full methodology process.

## Logistics

Participants were recruited through Involving People networks. All participants had lived experience of cancer, were family or care givers or worked with people with lived experience.

### Session 1:

- 6<sup>th</sup> December 10am to 12pm (online via Teams) – to demonstrate the system to participants prior to discussion.
- 5 participants.
- Facilitated by Involving People, system demonstration by inHealth Senior Account Manager and supported by NHS Dorset Digital Project Manager.

### Session 2:

- 6<sup>th</sup> December 2pm to 4pm (online via Teams) – to demonstrate the system to participants prior to discussion.
- 3 participants.
- Facilitated by Involving People, system demonstration by inHealth Senior Account Manager and supported by NHS Dorset Digital Project Manager and UHD Sister of Oncology.

### Session 3:

- 8<sup>th</sup> December 2pm to 3.30pm (online via Teams) – full discussion.
- 5 participants.
- Facilitated by Involving People, with NHS Dorset Digital Project Manager, UHD Consultant Medical Oncologist and UHD Sister of Oncology.

All participants were provided with a Participant Information Sheet (see proposal document), links to guidance on using Teams and an Equality Monitoring Form.

Participants were also provided with copies of the service leaflet, the draft user guidance, links to the project landing page and copies of the patient satisfaction questionnaire and “red alert” questions.

## Results

Points arising from the 2 demonstration sessions:

### Session 1/2

- What training would people receive prior to using the system?.
- Does the email/training state clearly that the system is not monitored real time 24/7?
- Can you change the weight question to stones/lbs – some people may have old scales?
- Will there be guides showing people how to take their blood pressure properly etc?
- Is there an opportunity to have a free text box so you can say what other symptoms/issues you may have that aren't in the questions? (e.g., problems with hands and feet or issues around passing urine).
- What's the difference between this system and the one that Weldmar have for example – could get confusing for people if they have multiple “systems”.
- Participants asked what the hospital sees from the system and what happens with that information.

- Participants needed more clarity about what happens out of hours (and felt this needs to be made very clear to service users).
- Participant with autism asked whether it would be possible to test the system before using it real time, to reassure themselves it works, and they are using it correctly. Without this there is a potential a patient may deliberately put in incorrect date to “test” the system. Will the training with the nurses be a “show and tell” or give patients the opportunity to “have a go” (autistic people often like to experience things rather than being told or shown – it’s more difficult to take in information without experience).
- Will patient information be available in easy read and other formats?
- Can there be videos that explain what “sharpness of breath is” or “chest pain” or will this be covered in the one-to-one training?
- Would the patient have “training” on how this system relates to/fits into other treatment they may be having for other conditions?
- If a patient ended up in A&E – would staff there know the patient was using the system and could see the results of their submissions?
- Some queries on how potential service users would be identified (e.g., if receiving cancer treatment but not through a separate oncology unit).
- Participants very interested that some aspects can be turned off – e.g., one participant advised they are always nauseous due to treatment and would not need to keep saying this or answering this on a questionnaire and keep getting red flags.

- Some concern this would take over from “normal clinical reviews” – after explanation from Sister stating it’s an extra layer of support, participants felt this needs to be made really clear to service users.
- Participants very positive about allowing people to stay at home and provide data rather than having to make a potentially long trip (when feeling unwell) into hospital just to tell staff everything is OK.

Note – Sister of Oncology provided a short explanation of what the training covers.

### Session 3 – Main Discussion

During this session several set questions were discussed (set and agreed by the OM@H project team).

Q1. What do you feel could potentially stop a service user using the system?

- Participants asked about people who have, for example, diabetes? Will there be anything specific for them to answer in terms of how treatment affects them?

**Project Team answer** – we will take forward to discuss in the team.

- Some participants felt the videos on the landing page are too long and seem to be generated for other projects/areas with information that may not be relevant.

**Project Team answer** – agreed. The intention is to create new videos specifically for this system that are 1 to 2 mins. Service users will receive training to use all the equipment (videos and written information will be a “back up” to the training).

- Participants felt users might need to be shown how to use the system more than once or be given the opportunity to test it (people often don't take in all the information they are given when first diagnosed, even if they may say they have, so having numerous opportunities to go through things is really important. Is this possible?

**Project Team answer** –it hasn't been anticipated for service users to test the system. It's more complicated technically as the test system and live system work slightly differently – whilst we don't want to presume we can't do this; it may be better reiterated to service users that there are numerous opportunities to come back to the team for more training. There is a helpline for users to call for help in using the system and we could potentially have a “phone back” mechanism for new users to reassure them they are using the system correctly or to offer further training if needed

- Participants asked whether it would be appropriate for users who aren't IT familiar to have a relative or care giver help them complete the questionnaires?

**Project Team answer** – absolutely with user consent although we are aware that a family member/care giver may have a different

perspective to a patient, so it is very important that the patient directs the answers – but yes it’s a reasonable compromise, in fact most people do have someone with them during their conversations with the nurse team anyway.

- There followed much further discussion on ensuring use of the number for the “hotline” and the number for the “helpline” are made very clear and details what each number covers and when they should be used. E.g., hotline (clinical) and helpline (IT and equipment) – that’s much clearer.

**Project Team answer** – we can take this onboard for the literature and it will be made clear in the training as well. The leaflets will be printed for all patients (they were never intended to be just electronic) so the font can be changed etc in the next iteration.

- Some participants expressed concerns for people who may find it hard to hear smartphones so it’s good that there will be an automated landline.

**Project Team answer** – yes this will be an option but it’s very time consuming, so the preferred option is to encourage (wherever possible) people to use the app or email version (click link to the system). There will also be a text version which will also include a link to click on to use the system.

Q2. How can we make it clear that if the system is down, users are still able to call the hotline?

- Participants felt it wasn't really clear in the information they had seen. It would be useful to have a banner pop up if there are system issues.

**Project Team answer** – This will be the case for scheduled maintenance but obviously not possible to do this for unforeseen issues. We need to make it clearer that the hotline is separate from the actual system and, as such, will always be available and for people not to worry.

Q3. How can we make sure that patients do not presume that the system is being monitored in real time 24/7?

- Participants felt this needs to be made clear in the training session and reiterated through the written information and also on a regular basis through the usual general discussions with users (at clinics etc) in case they forget. Messaging needs to be explicit and consistent.

**Project Team answer** – Although the system is not monitored in real time, hospital staff will be checking the system on a regular basis so it is possible that a user will receive a call back out of hours. It is important that users are aware this may happen, but it's not guaranteed. We are aware that some people may not call the hotline even if the system tells them to so if the user has had an alert

advising them to call and they haven't within 2 hrs, they will receive a call from the hospital to check everything is OK.

- Some participants felt the 2 questions relating to the alert were not clear, although they accepted this may be different if they were actual service users.
- **Project Team answer** – we're not sure the wording can be changed now but we will monitor and see what the actual service user feedback tells us.

Q4. Would patients be falsely reassured if, despite advice telling them to ring the hotline, no one from the hospital rings back?

- Some participants advised that if they had called the hospital and left a message (due to a red alert) and didn't receive a call back, they would assume there was a problem, but not everyone may think this way – some people may think everything is OK.

**Project Team answer** – the system tells people that if they haven't heard back in 30 mins please call again – it's not ambiguous at all.

Further general discussions items:

- When asked if participants felt users may ignore symptoms if they are not on the questionnaire, they agreed that as long as the system is really clear that if someone is concerned about anything (and states "even if not mentioned here") they should call the hotline, they felt this should be sufficient.

- Looking at the user guidance, participants felt that it either needs to be very clear that it shows some examples only or alternatively it should go through every stage.
- Participants felt it needs to be clear that the helpline number also covers any equipment problems, not just IT issues.
- Further to the focus groups, a participant asked, “when a patient submits their vital/soft signs will they see that the data has been received and checked (by a named individual - to assure accountability) in order to provide them peace of mind?”