



Systematic hospital collection of patient-reported outcome data via patient apps

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Abstract

Medical writers are increasingly likely to come across patient apps in their work, and we describe here the background and use of two apps for assessing patient-reported outcome (PRO).

Systematic collection of PRO data via patient apps has been recently introduced in a large Danish university hospital. Experiences so far show that the approach can help staff to focus on the individual patient's needs and can improve communication between patients and staff. Some patients have also been able to avoid unnecessary hospital visits.

Effective clinical use of systematic PRO data requires the data to be easily accessed and visualised, and both patients and staff need to know that the data provided will make a meaningful contribution to health care.

Patient-reported outcome (PRO) measures have been used for some time in the Danish healthcare sector, with patients completing questionnaires about their health and treatment experiences. This has mostly occurred through research projects, and questionnaires have traditionally been in paper form and sent through the post or completed at the clinic. The last few years have seen major changes, however, primarily in the way the questionnaires are completed, the breadth of PRO use, and the ambition

level for using the data that are collected.

This change in PRO use is partly a result of developments in the Danish Healthcare Quality Programme that was introduced in 2004.¹ This programme aims to ensure continuous development of the quality of care to create better patient pathways and to prevent errors and unintended events in the healthcare system. Two fundamental objectives of the programme are to involve the users – patients and their relatives – in healthcare decisions and to ensure a patient-centred culture within hospital departments.

A main strategy in the 2015 to 2018 national quality programme is to work towards the systematic use of cross-sector PRO measures with the aim of directly influencing treatment decisions and ensuring quality of care.² Such PRO data should include patient-reported symptoms, self-assessed health, and treatment experiences and should enable assessment of the effect of a treatment or health intervention.

This means that it will be essential to collect valid, reliable data to guide decision-making and the development and evaluation of health services. The systematic use of PRO data is generally seen as a positive step, but it is still a developing concept, and as yet there is no national consensus on which PRO measures should be used and in what format.

Systematic PRO data as a priority at OUH – Svendborg Hospital

Odense University Hospital (OUH) and Svendborg Hospital together provide local and acute services for the Danish island of Funen. They represent the largest referral hospital in Southern Denmark, with all medical specialties, approximately 1,000 hospital beds, and about

1 million outpatient visits per year (data from OUH management). In addition, OUH takes patients from all over Denmark due to its highly specialised services.

OUH and Svendborg Hospital have prioritised the systematic collection of PRO data in the expectation that this will benefit patients – primarily through faster and more appropriate diagnostic pathways and fewer, more targeted follow-up visits. PRO data have been key aspects of clinical research for some time, for example the collection of EQ-5D data alongside measures of functional independence and physical mobility for patients undergoing orthopaedic surgery,³ the development of a quality of life questionnaire for thyroid disease,⁴ and quality of life in toddlers with middle ear disease.⁵ Systematic collection of PRO data is not without its challenges, however, including lower completion rates for elderly patients with impaired cognitive skills,³ and the need to reassure healthcare staff that the PRO data make a meaningful contribution to the individual patient's care.⁶

OUH has recently established a networking group for departments using PRO measures on a systematic basis. This means that departments can help each other and can draw from each other's experiences using PRO measures. "The

departments are very positive. Most of them use PRO measures that have already been developed, which is of course the easiest solution. Others will have to develop new measures, and that is a challenge. But they can take advantage of the experiences we already have and can use the existing PRO measures as a starting point", says Jon Sigurjónsson, PRO consultant at OUH.

The availability of electronic platforms has significantly changed PRO data collection. Instead of developing paper-based PRO questionnaires for a single purpose and then discarding them after the requisite number of years, the data can now be collected via platforms such as RedCap or apps on mobile devices that facilitate storage, analysis, and feedback.⁷ Many of the PRO measures that will be used for systematic data collection at OUH will be implemented through the regional app, "My Patient Journey".

My Patient Journey – an app for patients and medical staff

The "My Patient Journey" app was developed in 2014 at the Centre for Innovative Medical Technology at OUH for easier digital communication between patients, medical staff, and hospital departments.⁸ The app helps patients find and keep track of information from the hospital and aims to give them a better overview and experience in communicating with the hospital. Today, it is in use all over the Region of Southern Denmark by approximately 44,000 patients and 2,000 clinicians (data extracted from "My Patient Journey"). The app is primarily for patients, but it can be downloaded from Google Play or App Store (as "Mit forløb").

The "My Patient Journey" app is now the user interface for patients at OUH. Patients can send text messages to medical staff and can access information about their own treatment in the form of text, videos, and images (thus replacing

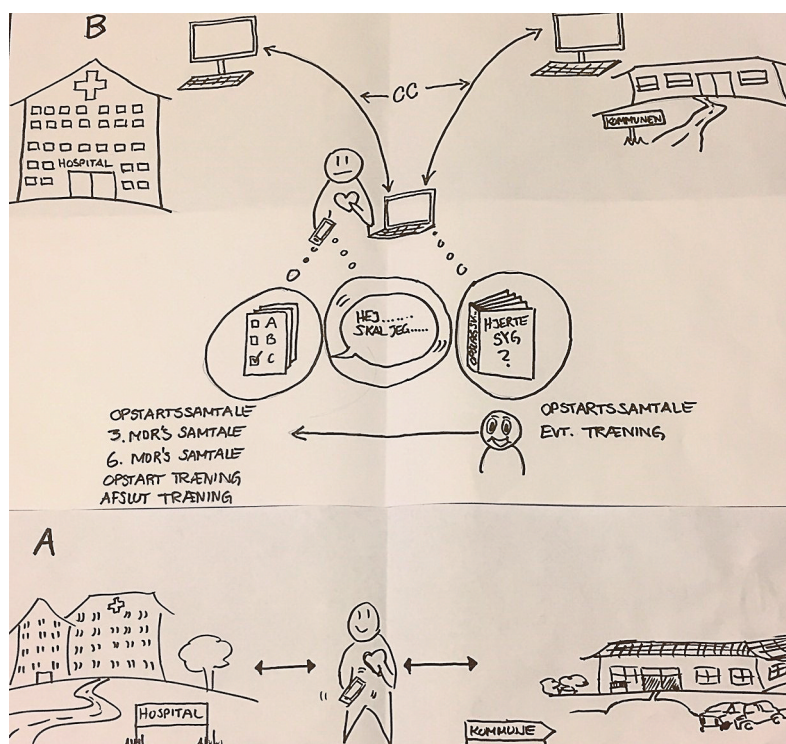


Figure 1: Comparison of the old and the new follow-up systems for patients who have undergone a cardiology intervention

A (lower picture): the 'old' - the patient visits the hospital and the municipal rehabilitation service in person. B (upper picture): the 'new' - the patient sends health status data to the hospital and the municipal rehabilitation service, who then advise on the form and frequency of follow-up.

the more general paper pamphlets). The app is also a platform for the patients to enter data – such as weight or blood pressure – and for answering questionnaires uploaded by the medical staff.

The nursing staff are the main operators of the app in the hospital. The app has been integrated into the electronic medical journal that is already used on a daily basis for recording patients' visits and information and for exchanging data with other hospital departments, general practitioners, and the municipalities.

The "My Patient Journey" app can be adapted to the specific needs of the hospital department and for selected patient groups. Clinical departments are thus free to choose which PRO measures and other questions should be included. This is typically done with patient involvement to ensure relevant data collection and minimal respondent burden. The emphasis for PRO measures is on existing, validated health and quality of life questionnaires.

When questionnaires are applied within the "My Patient Journey" app, an algorithm can be created that calculates a score based on the individual patient's answers. The patient's score can then determine how the medical staff should follow up with the patient.

A PRO app for patients in a heart rehabilitation programme

The cardiology clinic at Svendborg Hospital has been running a pilot PRO project in a partnership with the municipal rehabilitation services. This is a cross-sector collaboration where the responses that patients make to the medical staff's questions and to the PRO measures are made available to the hospital department and the municipal rehabilitation services at the same time (Figure 1).

The two PRO measures used in this project are the Hospital Anxiety and Depression Scale (HADS) and the HeartQoL. Both have 14 items; the HADS can be used to identify persons at risk of clinical anxiety or depression, while the HeartQoL was developed by the European Association of Preventive Cardiology for patients with ischaemic heart disease. The department has been collecting patient data using these PRO measures for some time, but in paper form.

In this project, the PRO measures are loaded

into the "My Patient Journey" app, and patients who have undergone a cardiology intervention are asked to complete them at the first nurse consultation (about two weeks after the intervention) and again after three and six months. In the meantime, the patient is referred to a rehabilitation programme including exercise training and education on healthy living with heart disease.

The objective of the project is to see whether the PRO data can enrich the patients' contacts with the hospital and municipal services through more relevant discussions and treatment. This may be in the form of a more individualised rehabilitation programme or interventions for anxiety, depression, cessation of smoking, weight loss, etc.

The 30 patients who have participated in the project so far have given positive feedback. They like the easy interactive format where they can just send an SMS to the nurse they know to ask about something in their daily life, and they know that the nurse's answer is based on the patient's current health and status. They also feel better prepared to talk to the nurse at their next consultation and to discuss health and emotional issues.

The nurses have found it easier to prepare for consultations with patients and can focus the discussion on the issues that the individual patient is currently facing. The PRO data enable the staff to stratify patients earlier on, and patients who are doing well and do not need close follow-up can avoid unnecessary hospital visits. The advantages for the rehabilitation staff are that the patient-reported data on problems and challenges help them to better plan the rehabilitation programme in advance, provide a way of following the patient's progress, and can identify areas that need more focus.

An issue still requiring attention is the response rate to the PRO measures completed via an app, as some patients were less accepting of this approach. These were especially older patients who were less familiar with smartphones and tablets. This will be one of the aspects to be evaluated during the next phase of the project,

which is introducing the PRO app into routine clinical use.

A PRO app for patients undergoing prostate cancer surgery

Following a successful two-year project,⁹ a PRO app is now used routinely with patients undergoing prostate cancer surgery at the urological ward at OUH. Using "My Patient Journey" as a platform, patients answer the questions electronically from home both before surgery and again at 3, 6, and 12 months after surgery. The questionnaire has been developed by a national working group under the Danish Health Authority and is aimed at all patients with prostate cancer regardless of the type of treatment they get. At the same time-points, the patient also has a blood test taken by the general practitioner. The PRO app scores the patient's answers, and the resulting score and blood test results give a colour-coding for whether telephone or outpatient follow-up is necessary (orange or red) or not necessary (green), see the example in Figure 2 overleaf. The objective here is to use the PRO data to reduce the number of unnecessary hospital visits.

This approach has been a great success. The use of the PRO data has eliminated two-thirds of the follow-up visits in this patient group, thus giving the staff more time for patients with more complicated problems and reducing the waiting lists.

The patients report that the app helps them to be more active and involved in their treatment and discussions with hospital staff. The app approach appears to be especially beneficial for elderly patients, who can now send a picture or a video via "My Patient Journey" instead of having to make the trip to the hospital. An important element, however, is that patients can see that the medical staff have made active use

of the PRO data, and that the data are not just collected and then stored.

Next steps include broadening the use of the PRO app, for example to patients with prostate cancer who are being treated with medicines

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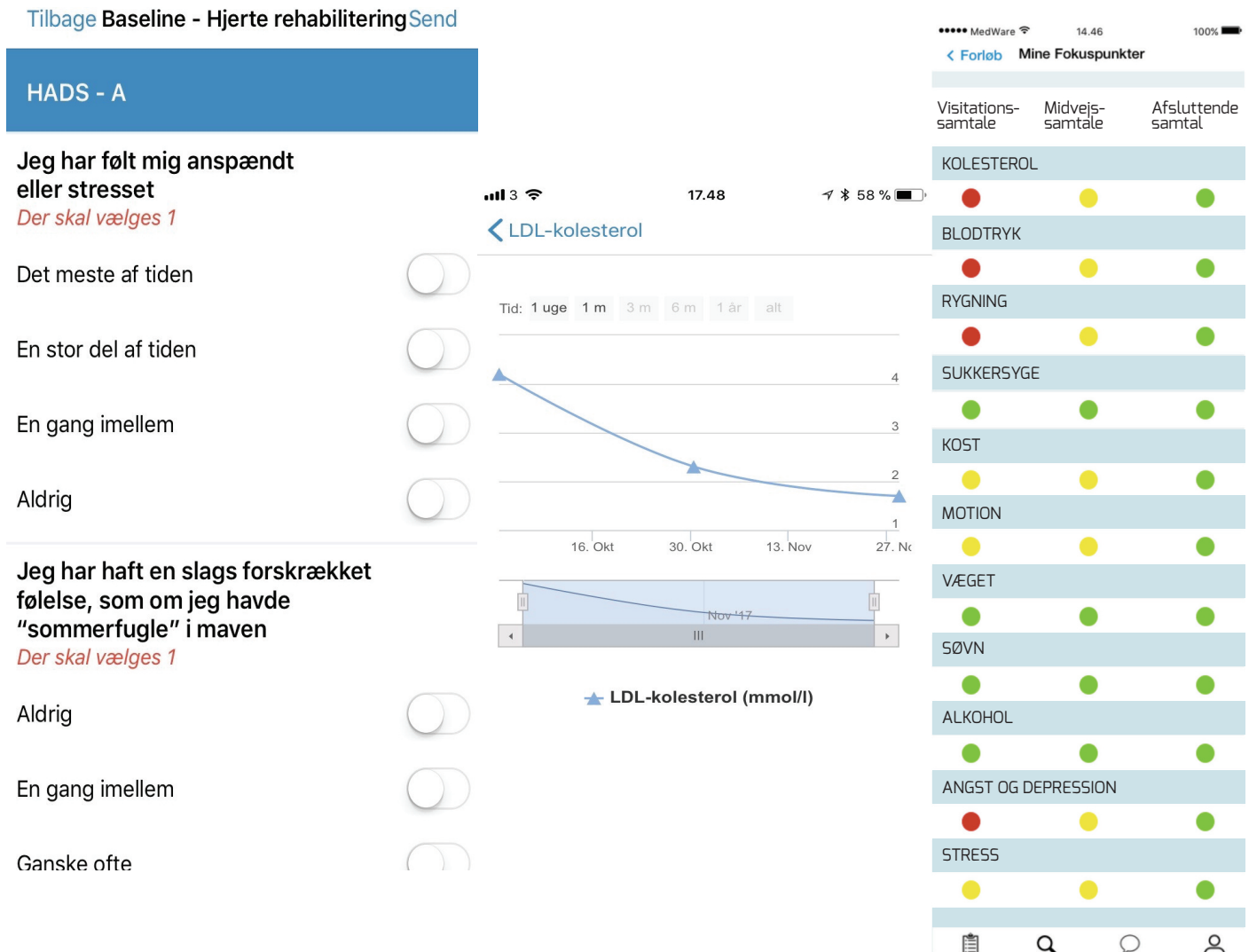


Figure 2: An example from the cardiology project of how PRO app data can be used

Here, questions from the Hospital Anxiety and Depression Scale (HADS) are combined with blood test results (here on cholesterol level) to stratify patients at follow-up to RED (current problem, needs immediate attention), YELLOW (current problem, needs follow-up), or GREEN (no current problem). In this example, the patient has several "red" and "yellow" issues at the first visit, and these improve to green over time.

English translation:

Baseline – Heart rehabilitation: HADS questions (Choose 1 answer): *I feel tense or "wound up"*: Most of the time / A lot of the time / From time to time, occasionally / Not at all. *I get a sort of frightened feeling like 'butterflies' in the stomach*: Not at all / Occasionally / Quite Often / Very Often

My focus points [for] Initial – Midway – Final Consultation: Cholesterol – Blood pressure – Smoking – Diabetes – Diet – Exercise – Weight – Sleep – Alcohol – Anxiety and depression – Stress

rather than surgery. This may be more challenging in terms of resources, as the PRO app is not expected to reduce visits and it takes time for the medical staff to go through the patient's answers to the questionnaire and discuss them as appropriate.

PRO measures are the future

"It is not a question of whether or not we should use PRO measures. We should definitely use

them and much more than today – in every department in the hospital", says Kim Brixen, medical director at OUH. "It provides possibilities for better and faster diagnostics in addition to fewer and better follow-ups. PRO measures are also useful for collecting research data, which is especially valuable for a university hospital. Depending on the patient's diagnosis, I believe that many outpatient visits can be replaced by PRO surveys."

Another potential advantage of the app approach to PRO data collection is in clinical research projects, where patients with baseline PRO data can easily be block-randomised and divided into intervention and control groups.

There are notes of caution when using PRO apps, however. One is the tendency to focus on the specific health issues that emerge from the patient data, thus potentially missing important information that is not asked about. A similar

problem can arise with telephone and e-mail consultations and from telemedicine, as the full picture of a person's health is only achieved through a (well-performed) traditional consultation. This is an issue that requires further research, as it could have negative effects on patient treatment.

A further issue is the extent to which the PRO measures should be piloted and validated before the hospital initiates large projects or implements routine data collection. In many countries, PRO questionnaires are typically put through a long testing process before they are used. OUH has decided to test the use of PRO measures in “real life”, however, by putting them into use and correcting any errors as they are identified.

While Denmark is known for its comprehensive system of health registers that can be linked through the individual personal identifier, it is recognised that the sharing of PRO data between patient and medical staff, and between hospital sectors, has to be done with care and attention to individual privacy. Written informed consent to share the PRO data is typically done through the PRO app. The patient is presented with relevant information, and this needs to be registered in the app as “read” before it is possible to give consent. Consent can also be withdrawn through the app. The issues surrounding data privacy and informed consent may become more prominent as the sharing of personal health data becomes more widespread.

Conclusions

There is still much to learn about the systematic collection of patient-reported outcome data via apps as an aid to optimising healthcare treatment and care. However, it appears to be a promising approach for focusing on the individual patient's needs and current status and for improving communication between patients and healthcare staff.

An important next step is the more formal evaluation of the PRO app projects. The cardiology project described here is currently being evaluated using the Model for Assessment of Telemedicine approach. This involves assessment of several aspects such as the clinical effects, patient safety, the patients' perspectives and experiences, financial aspects, and organisational effects.

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Conflicts of interest

The authors declare no conflicts of interest.

References

1. The Danish Healthcare Quality Programme (DDKM). Imaging Management. 2010;12(5). Available from: <https://healthmanagement.org/c/hospital/issuearticle/the-danish-healthcare-quality-programme-ddkm>.
2. Danish Ministry for Health and Prevention [in Danish]. [Nationalt Kvalitetsprogram for Sundhedsområdet 2015–2018]. 2015. Available from: https://www.sum.dk/~media/Filer%20-%20Publikationer_i_pdf/2015/Nationalt-kvalitetsprogram-for-sundhedsomraadet/Nationalt%20kvalitetsprogram%20for%20sundhedsomr%C3%A5det%20-%20april%202015.ashx.
3. Pedersen TJ, Lauritsen JM. Routine functional assessment for hip fracture patients. *Acta Orthop*. 2016;87(4):374–9.
4. Winther KH, Cramon P, Watt T, Bjørner JB, Ekholm O, Feldt-Rasmussen U, et al. Disease-specific as well as generic quality of life is widely impacted in autoimmune hypothyroidism and improves during the first six months of levothyroxine therapy. *PLoS One*. 2016;11(6):e0156925.

5. Indius JH, Alqaderi SK, Kjeldsen AD, Heidemann CH. Middle ear disease in Danish toddlers attending nursery day-care: applicability of OM-6, disease specific quality of life and predictors for middle ear symptoms. *Int J Pediatr Otorhinolaryngol*. 2018;110:130–4.
6. Pedersen TJ, Kristensen HK. A critical discourse analysis of the attitudes of occupational therapists and physiotherapists towards the systematic use of standardised outcome measurement. *Disability and Rehabilitation*. 2016;38(16):1592–602.
7. Svendsen MT, Andersen F, Andersen KH, Andersen KE. Can an app supporting psoriasis patients improve adherence to topical treatment? A single-blind randomized controlled trial. *BMC Dermatol*. 2018;18(1):2.
8. MedWare ApS. My Patient Journey. Accessed 28th August 2018. Available from: <http://www.medware.dk/en/project/my-patient-journey/>.
9. The Danish Cancer Society [In Danish]. [Klinisk anvendelse af Patient Reported Outcome Measures (PROM) – en evalueringsrapport]. 2016. Available from: <https://www.cancer.dk/dyn/resources/File/file/9/6659/1505726340/klinisk-anvendelse-af-patient-reported-outcome-measures-prom.pdf>.

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