SHARING IS CARING: USING A DATA HUB TO INFORM TREATMENT DECISIONS BASED ON SYMPTOM MONITORING DATA

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INTRODUCTION

Patient-reported symptom monitoring has proven to be effective in reducing side-effects and improves health-related quality of life (HRQoL) and survival.[1] In the PRO-lung project patients use the SYMPRO application to monitor symptoms based on the PRO-CTCAE and an alert is issued if a symptom exceeds a predefined threshold.
In Dutch hospitals many applications are used to capture patient-reported outcomes (PRO), introducing an undesirable variety of methods.
The PROMOTE PRO-lung project aims to
1. accelerate implementation of symptom monitoring in Dutch health care to get it available for many patients with lung cancer
2. build an infrastructure in PROFILES registry to share data for secondary purposes.

METHODS

We developed an open-standards based methodology for symptom monitoring and data reuse. This methodology is suitable for implementation in both commercial and non-commercial applications. In the PROMOTE PRO-lung project commercial applications adopt the PRO-lung methodology. Data quality from the several application providers is audited. The PRO data are linked to the Dutch Cancer Registry (NKR) to include clinical information. Hospitals using commercial applications now manually transfer data to a central database, but efforts are being made towards automated data exchange; In the future pseudonymized data are exchanged in a PRO database using the Fast Healthcare Interoperability Resources (FHIR) standard. The Personal Health Train approach can be used to send queries and receive answers to (research) questions from PROFILES and NKR (Figure 1).
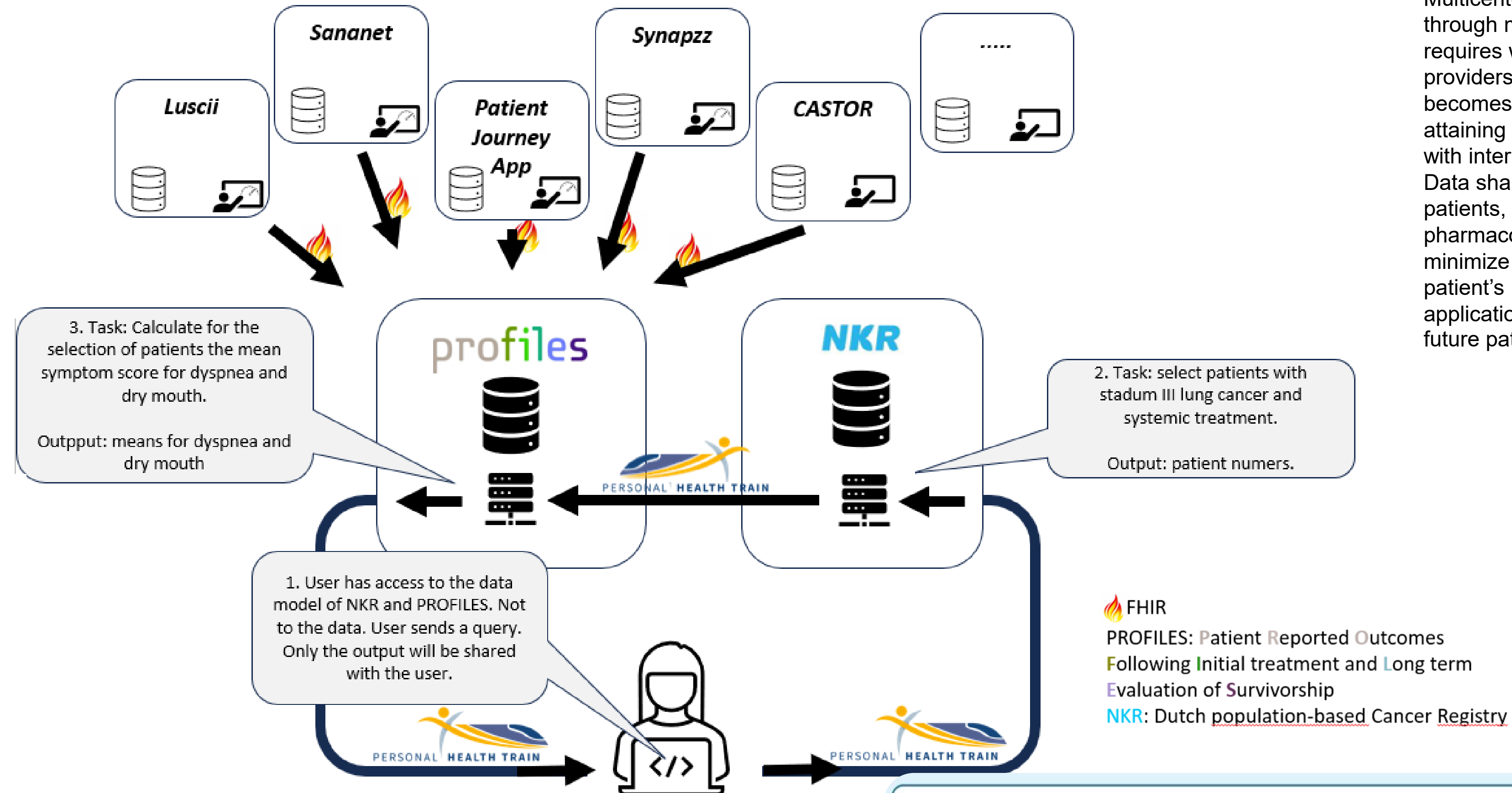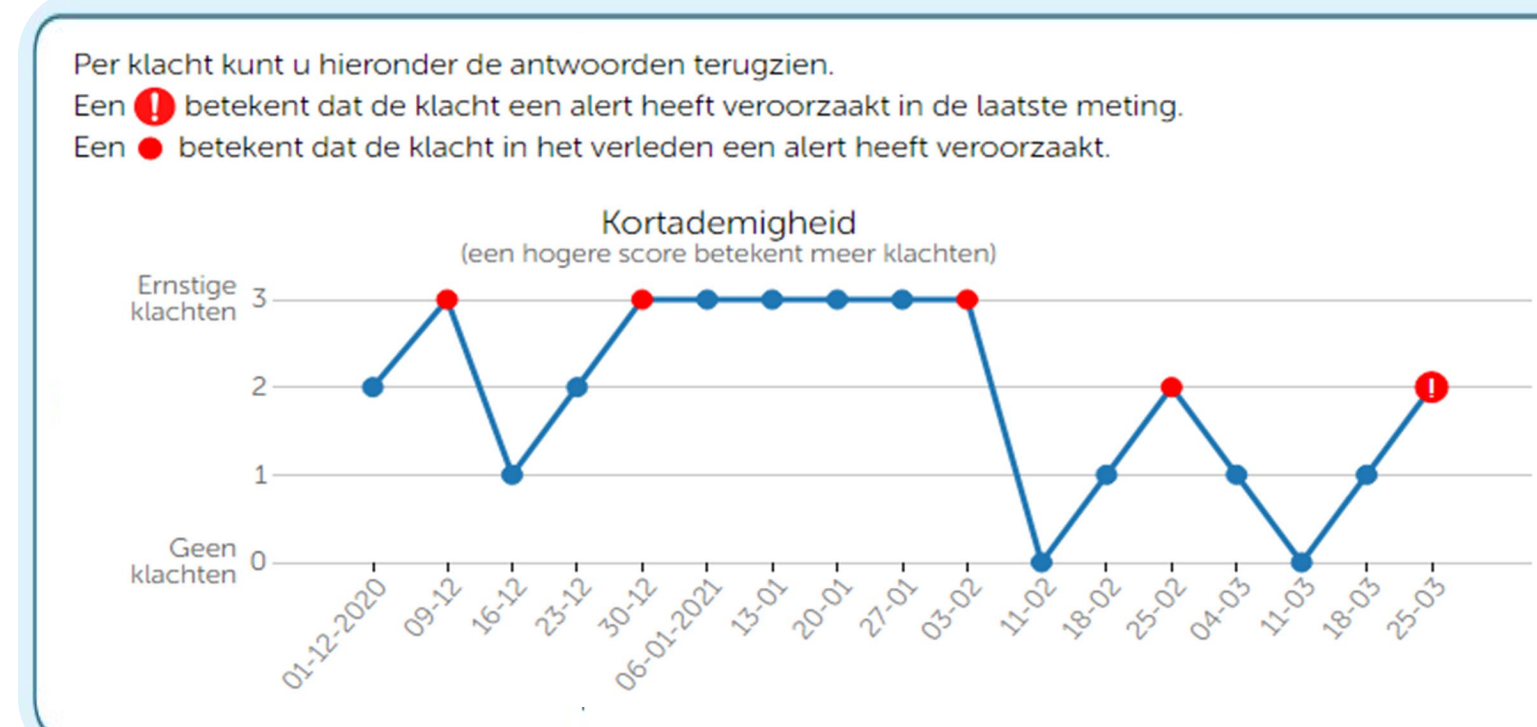
RESULTS

PRO-lung has included 116 patients in 10 Dutch hospitals. The first commercial application started data collection in May 2024 and a second one will start later this year. Data will primarily be used for individual patient care and secondary for shared decision making and research.

CONCLUSION and NEXT STEPS

Multicenter patient-reported data collection through multiple applications in first place requires willingness of patients and healthcare providers to share data. The technical aspect becomes feasible solely through standardization, attaining its utmost sustainability when aligned with international guidelines.
Data sharing will provide health care providers, patients, policy makers, researches and pharmacovigilance staff with real world data to minimize symptom burden and optimize the patient's HRQoL. This shows how a simple application for use in daily care adds value for future patients.

Sananet

Synapzz

.....

Luscii

Patient Journey App

CASTOR

profiles

NKR

3. Task: Calculate for the selection of patients the mean symptom score for dyspnea and dry mouth.

Outpput: means for dyspnea and dry mouth

2. Task: select patients with stadium III lung cancer and systemic treatment.

Output: patient numers.

1. User has access to the data model of NKR and PROFILES. Not to the data. User sends a query. Only the output will be shared with the user.

PERSONAL HEALTH TRAIN

FHIR
PROFILES: Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship
NKR: Dutch population-based Cancer Registry

profiles

Voortgang

Hoe **erg** was uw **verminderde eetlust** op het **slechtste moment** de afgelopen 7 dagen?

Helemaal niet
Een beetje
Matig
Erg
Heel erg

← vorige   verder →

Per klacht kunt u hieronder de antwoorden terugzien.
Een ❗ betekent dat de klacht een alert heeft veroorzaakt in de laatste meting.
Een 🔴 betekent dat de klacht in het verleden een alert heeft veroorzaakt.

Kortademigheid
(een hogere score betekent meer klachten)

Ernstige klachten 3

2

1

Geen klachten 0

01-12-2020 09-12 16-12 23-12 30-12 06-01-2021 13-01 20-01 27-01 03-02 11-02 18-02 25-02 04-03 11-03 18-03 25-03

[1] N. Billingy et al. Quality of life after patient-initiated vs physician-initiated response to symptom monitoring: the SYMPRO-Lung trial. J Natl Cancer Inst. 2023