From dialogue to decision

Using technology to facilitate shared decision-making in a fall prevention context

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CHAPTER 2

SeNiors empOWered via big Data to joint-manage their medication-related Risk Of falling in Primary care:

The SNOWDROP Project

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Abstract

In older persons, falls are the leading cause of injuries, often resulting in emergency room visits, serious injuries, and possibly even death. Medications are a major risk factor for falls. Because we lack tools to assess individualized risks, general practitioners (GPs) struggle with fall related medication management for seniors, and senior patients are not properly equipped to engage in the joint management of their medications. Our aim in this project is to develop and evaluate a comprehensive data-driven science approach for valid prediction of personalized risk of falling that effectively supports joint medication management between seniors and GPs. The project has two objectives. First, we aim to develop and validate prediction models from electronic health records for assessing individualized risk of medication-related falls. Data science challenges include free text analysis; accounting for missing values; searching medication hierarchies; engineering new predictors, and understanding limitations of our approach. Second, we aim to develop and evaluate a joint medication management strategy for older patients and GPs, consisting of a clinical decision support system (CDSS) and a patient portal. We evaluate the effects of this strategy on changes in the quality of shared decision-making during a medication review consultation, medication management, and patient outcomes. The learnings from this project and the architecture underpinned by predictive modelling to support both GPs and patients can also be applied to other major health problems in the future.

Introduction

An important ongoing transformation in public health is a shift from a disease-centered to a patient-centered approach, and from single-disease-focused to multi-disease-focused care. This transformation requires high quality shared decision-making (SDM) between patients and clinicians. During the SDM process healthcare related decisions are made by the patient and healthcare professional together, exploring the best available treatment options and the patient's goals (Elwyn et al., 2017). SDM is particularly important in the context of medication management among older patients. Older people use a relatively large number of medicines and are sensitive to side effects. Falls are a prevalent side effect and are the leading cause of traumatic injury among older people (Vu et al., 2020). Just in the Netherlands in 2022, every 4 minutes an older person (65 years and older) was admitted to the emergency room due to a fall, 87,000 older people were seriously injured (e.g. brain damage, hip fractures), and 5995 older people died because of a fall (VeiligheidNL, 2022). Furthermore, falls can set off a downward spiral, where fear of falling can trigger reduced activity, and hence impaired balance, and decreased strength, ultimately leading to a lower quality of life (Soriano et al., 2007).

Certain medications are recognized as an important -but modifiable-predisposing factor for falls (also called Fall Risk Increasing Drugs; FRIDs), providing an opportunity to minimize the fall risk when appropriately managed (Ham et al., 2014; Michalcova et al., 2020). It is therefore important that general practitioners (GPs) and older patients regularly evaluate medication use together. However, GPs lack tools to assess individualized risks, and struggle with fall-related medication management for older patients. Older patients, in turn, are often not properly equipped to engage in SDM to reduce their fall-risk. An explanation for this might be the lack of knowledge; about 85% of older patients with polypharmacy do not know the indication of their prescribed medication (Bosch-Lenders et al., 2016). Polypharmacy entails taking multiple medications (e.g. five or more) simultaneously (Masnoon et al., 2017). In this interdisciplinary project, called SNOWDROP (SeNiors empOWred via big Data to joint-manage their medication-related Risk Of falling in Primary care), we aim to achieve two objectives: to develop and validate prediction models for falls in older patients that can be used to estimate individualized fall risk (WP1; data science), and to use these prediction models to provide smart decision support for shared decision making between GPs and older patients (WP2; communication science). A visual representation of both parts can be found in Figure 1.

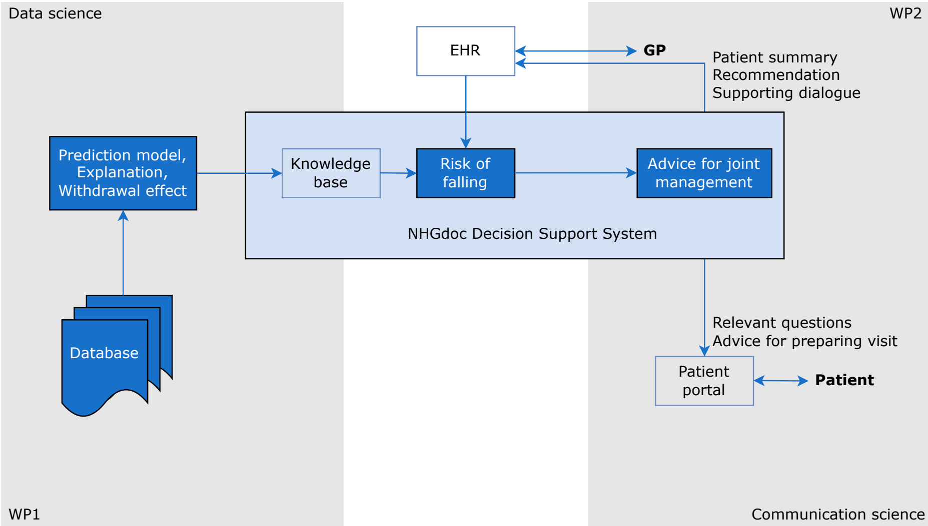

Figure 1. Visualized overview of data science (WP1) and communication science (WP2)

SNOWDROP spans a wide range of research and development activities relevant to medical-, data-, and communication sciences. In the data science part (WP1), we address the analysis of routinely collected "messy" data in the electronic health record (EHR) of the GPs, mining clinical notes, handling missing values, searching for potential predictive variables, and ultimately using statistical machine learning techniques to develop and validate prediction models for falls.

In the communication science part of the project (WP2), based on the prediction models obtained in WP1, personalized decision support about the risks of individual patients' medication will be provided to the GP via a clinical decision support system (CDSS). Patients, in turn, will be supported through a patient portal to prepare for the medication review consultation that they will be invited to. In WP2, both systems are systematically developed according to user-centered design (UCD) principles. UCD entails involving end users in all phases of the development process, to make sure the end product fits their needs and wishes seamlessly (Brunner et al., 2017; Nazi et al., 2018). We investigate the effects of the intervention on, for instance, SDM in a randomized controlled trial (RCT) in which older patients and GPs in the intervention group will receive the full intervention consisting of both systems (the CDSS and the patient portal), while patients in the control group will receive usual care. The health communication researchers are experts on, for instance, doctor-patient communication (including the SDM component of the SNOWDROP intervention), motivating patients and healthcare professionals to use the intervention, and persuasive health technologies, including the use of UCD methods to ensure that the intervention fits the needs and wishes of the users in order to increase acceptance/compliance.

Methods

The first objective of SNOWDROP is to develop and validate a prediction model for falls in patients aged 65 or older using EHR data collected from GPs in the Netherlands. The EHR data comprise demographics, diagnoses, prescribed medications and clinical notes written mainly by GPs. A prediction model is a mathematical formula that connects various predictors related to a specific individual to estimate the likelihood of a particular outcome (falls in our case) in the future (Moons et al., 2015). It is important to note that predictive models are designed to estimate the likelihood of an event based on specified variables. Unlike causal inference, which was not the primary objective here, predictive modeling does not necessarily require adjusting for confounding factors. Causal inference, on the other hand, specifically involves understanding how the likelihood of an event changes when we intervene by altering a predictor, often necessitating careful adjustment for confounding factors to ensure accurate conclusions. Furthermore, the prediction model in this project is solely used to identify patients at risk of falling. The recommendations that are subsequently provided by the CDSS are based on guidelines.

Potential predictors (i.e., input for the prediction model) for falls were identified according to the literature and expert knowledge. Lab measurements were excluded from the analysis due to a high percentage of individuals lacking measured values (46%-100%). Attempting fall prediction with imputed values did not enhance performance. Using the XGBoost machine learning algorithm (Chen & Guestrin, 2016), which accommodates missing values, did not render these variables predictive. We used two independent cohorts, namely the development cohort and the validation cohort, to develop and assess the generalizability of our prediction model. The development cohort contained data on 36,470 older patients enlisted with 50 GPs, and the validation cohort contained data on 39,342 older patients enlisted with 59 other GPs. The validation step is necessary to justify the implementation of the prediction model in practice. The advantage of using a prediction model using EHR data is that it is based on variables that are routinely collected during medical care. As such, our prediction model can be integrated with a CDSS in an EHR system to identify patients at risk for which the CDSS can then provide (guideline-based) advice to manage FRIDs in order to decrease the fall risk. The specification of the knowledge base that underlies the pieces of advice to manage FRIDs was made in collaboration with the ADFICE_IT study (de Wildt et al., 2023).

We further applied Natural Language Processing (NLP) techniques to evaluate the incremental predictive value of the unstructured data (i.e., clinical notes) over the structured data (i.e., age, sex, and medication). NLP entails applying computational techniques for automated analysis of texts and spoken words (Chowdhary, 2020). Our approach relies on modern NLP techniques that translate words and documents into a vector representation, in order to capture their meaning. Specifically, we applied topic modeling (Churchill & Singh, 2022; RiahiNia et al., 2022) using Top2Vec [arXiv:2008.09470] to extract latent topics from the clinical notes. The resulting topics were used as input variables to a machine learning algorithm to predict future falls.

The second objective is to design and evaluate an SDM strategy for GPs and older patients. The prediction model, together with the advice, is embedded in NHGDoc, an existing decision support system that provides personalized information relevant to GPs via their EHR, and information relevant to patients via a patient portal. NHGdoc can connect to every Dutch GP information system except for one. This makes future implementation of the intervention easily feasible for the majority of Dutch systems. We evaluate the usability and the effects of this strategy on changes in the quality of the communication, in particular SDM, during a fall-related medication review consultation, medication management, and patient outcomes (e.g., beliefs about medicines, recall, and decisional conflict).

To make sure that the intervention is evidence-based and matches the needs and wishes of its end users (i.e. GPs and older patients), the Medical Research Council (MRC) guideline for complex interventions is followed (Skivington et al., 2021). This guideline consists of four phases; (1) development, (2) feasibility, (3) implementation, and (4) evaluation. In order to develop the intervention, a UCD approach is applied, meaning that end users are closely involved during all phases of the development process. During the development and feasibility phases, several UCD methods were applied. During the *development phase*, a systematic review concerning barriers and facilitators for using a medication-related CDSS as perceived by clinicians was conducted (Westerbeek et al., 2021).

Furthermore, interviews with older patients (*n* = 12 patients) and focus groups with GPs (*n* = 13 GPs) were performed to explore their needs and wishes for both systems and the intervention (Westerbeek et al., 2022). Based on these three studies, the first prototypes of the patient portal and CDSS were developed in collaboration with the partners Uw Zorg Online (formerly known as Pharmeon) and ExpertDoc, respectively (see section partners for more information on the collaborations).

In the second phase -*feasibility*- the first prototypes of both systems were tested. This was done by conducting individual usability tests with GPs (*n* = 5) to test the CDSS, and individual usability tests with older patients (*n* = 5) to test the patient portal, both using a think-aloud method. Participants (both GPs and older patients) were presented with hypothetical cases asking them to perform certain tasks while using the system. The think-aloud method that we used entails that while carrying out the tasks, GPs, and patients were prompted to think aloud and verbalize their thought processes. Afterward, participants were interviewed to gather additional feedback on the systems. Based on these usability tests, the prototypes were improved. This led to the third phase, *implementation*. Our partners, ExpertDoc and Uw Zorg Online, implemented the improvements and used this to develop ready-to-implement versions of both systems. GPs were trained on how to use the system and the intervention as a whole by means of a web lecture and an in-person training session.

The fourth and final phase -*evaluation*- consists of an RCT in which the complete intervention is tested. Six Dutch primary care practices participate in this RCT to test the SNOWDROP intervention. General practices are randomized to either the intervention condition or the control condition. Each participating GP is asked to perform +/- 14 consultations with older patients with a high fall risk to discuss their fall-related medication. GPs in the intervention condition receive the full intervention. The patients of the participating GPs in this condition prepare for their visit using the patient portal. GPs in the control condition are also asked to perform a medication review focused on the fall risk, but only receive a simple list of FRIDs. Consultations are audio recorded and analyzed for SDM. Patients fill out questionnaires prior to and after the consultation to assess secondary outcomes. These are beliefs about medicines, recall, and decisional conflict, technology acceptance, and website satisfaction. To check that the systems are actually being used during the RCT, we ask patients which components of the portal they used. For GPs, the audio recordings are checked for evidence that the system was used.

Key Results

With respect to the data science part of the project (WP1), we developed a prediction model for falls in older people using primary care EHR data (Dormosh, Schut, et al., 2022). The model was developed using Bootstrap-enhanced penalized logistic regression with the least absolute shrinkage and selection operator (Bach, 2008; Tibshiranit, 1996), and the prediction strategy was internally validated using 10-fold cross-validation. The model comprises ten predictors that were predictive for falls. These predictors are a combination of demographics, medication, and clinical conditions. The discriminative ability of our model, as measured by the area under the receiver operating characteristic curve (AUC), was 0.705. This performance compares favorably and often surpasses the performance of previously published models. Furthermore, our model performed well when externally validated on an independent cohort sample (AUC in the validation was 0.690), rendering it ready to be trialed in practice (Dormosh, Heymans, et al., 2022). Furthermore, we explored the predictive performance of topics that were automatically extracted from the clinical free-text notes written by GPs to predict falls, and their incremental predictive value over the clinical variables (Dormosh et al., 2023). We used modern NLP techniques that translate words and documents into a vector representation, to capture their meaning and extract the topics. The AUC of the model which incorporated both topics extracted from the clinical notes and clinical variables was 0.718 (CI 95% 0.708-0.727), and the AUC of the model that used only clinical variables was 0.709 (CI 95% 0.700–0.719). We found that the clinical notes form an additional viable data source to develop and improve prediction models for falls compared to traditional prediction models. The strengths of the abovementioned studies include the use of a large multicenter sample of older people to develop the model, conducting external validation which is rarely performed to assess the generalizability of the prediction models, and leveraging NLP and machine learning to extract information from the clinical notes to predict future falls.

For WP2, several key results have been obtained so far. The systematic review on barriers and facilitators for using a medication-related CDSS as reported by clinicians resulted in a very broad overview of barriers and facilitators. In total, 327 barriers and 291 facilitators were identified (Westerbeek et al., 2021). Salient barriers or facilitators (i.e. mentioned in more than one study) were aggregated, resulting in 195 unique barriers and 174 unique facilitators. These were categorized within the Human, Organization, and Technology-fit (HOT-fit) model. The results show that the most often reported (and presumably most important) barriers and facilitators were related to (a lack of) usefulness and relevance of information, and ease of use and efficiency of the system. We incorporated the findings of the systematic review throughout the design process; for example, we had a GP evaluate the formulation of every piece of advice to ensure that it was useful and relevant. Usability testing helped us to make sure the system was considered easy to use.

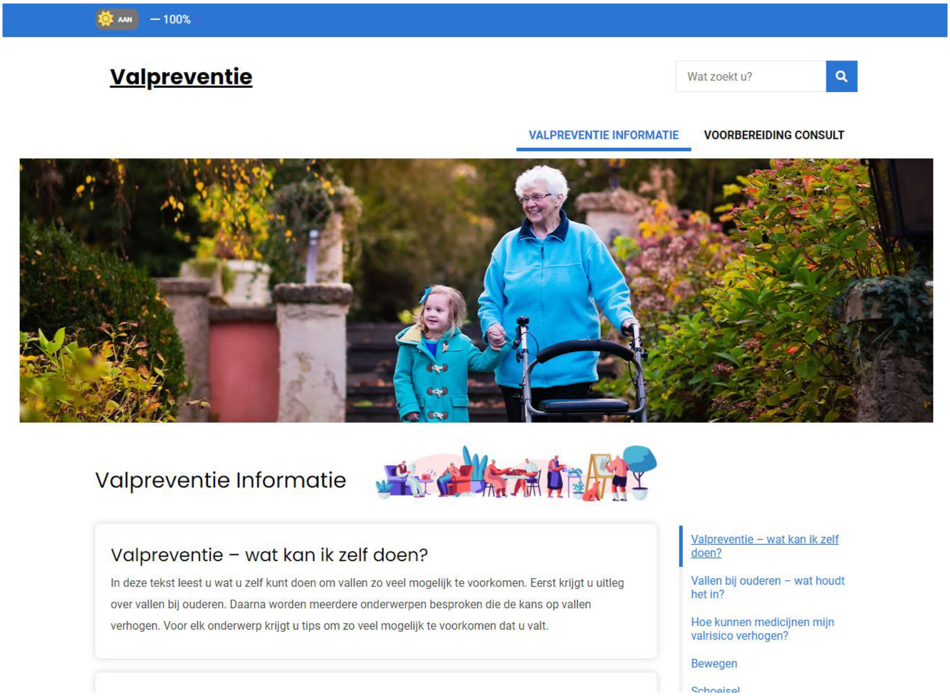

Figure 2. Patient portal

The interviews with patients and focus groups with GPs (Westerbeek et al., 2022) resulted in the first prototypes of the patient portal and CDSS. These were subsequently improved based on usability testing with a think-aloud approach and interview questions. Results of these studies informed the development and design decisions made in these systems. For instance, a visual presentation of the personalized fall risk, in the form of a gradient scale ranging from bright green to dark red, was incorporated within the CDSS based on the preferences indicated by GPs during the focus groups. Within the patient portal, a question prompt list was implemented. This allows the patient to prepare for the consultation by indicating which questions and/or concerns they would like to discuss with the

GP. Figure 2 displays the final, ready-to-implement patient portal, and Figure 3 displays the final, ready-to-implement CDSS, both of which are currently being tested in the RCT. Results of the RCT are expected in 2024.

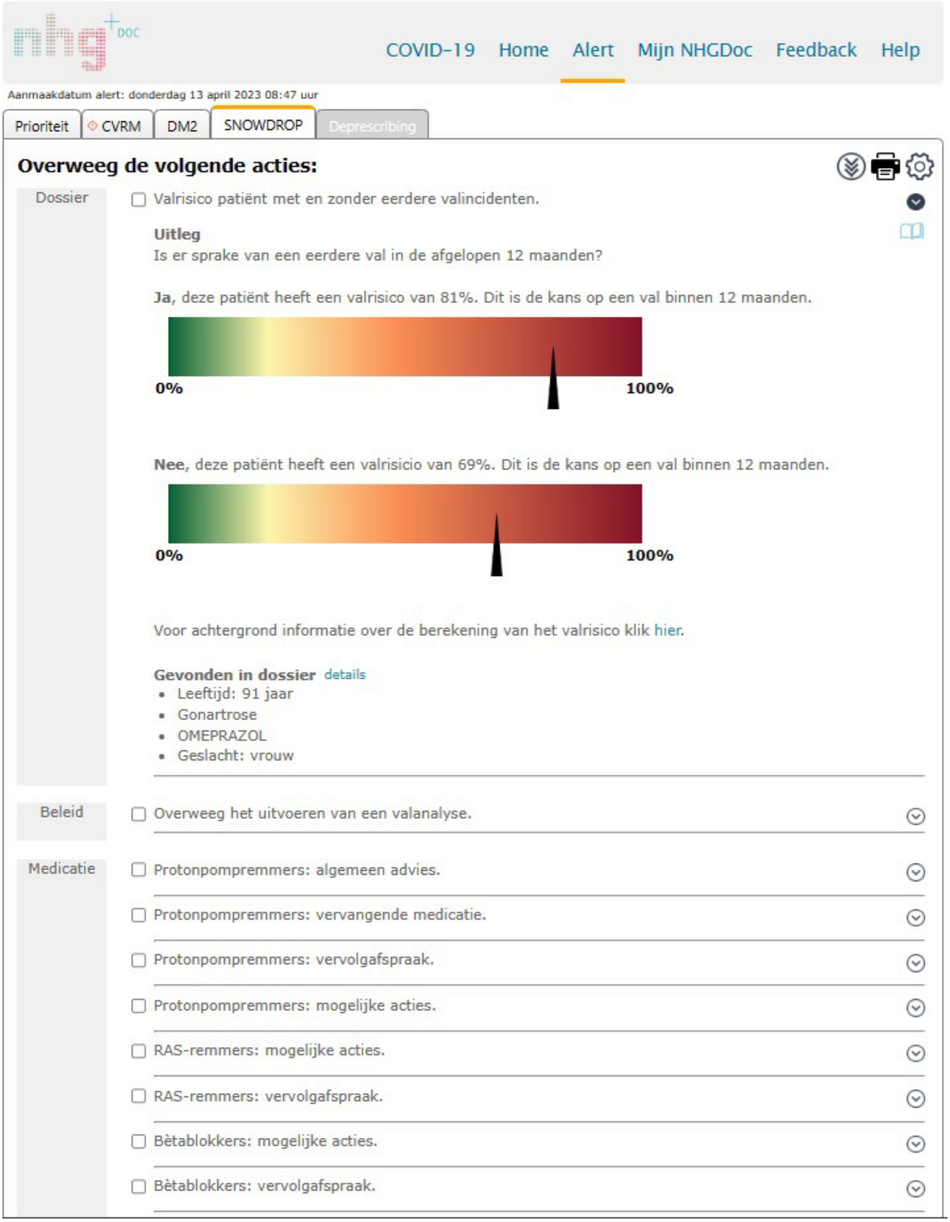

Figure 3. CDSS

Discussion

Partners

To achieve the abovementioned objectives, we collaborate with three private partners: Elsevier, ExpertDoc and Uw Zorg Online. The motivation of these private partners to participate in this study stems from their vision of the future of healthcare and the role that they would play in it. Investigating and shaping new models for delivering healthcare and the role that technology plays aligns perfectly with our research agenda. First, Elsevier is proactively searching for new “publishing” opportunities in terms of disseminating knowledge. As a publisher, they would like to explore the move from “read this” to data-driven, patient-specific, timely “do this” recommendations to disseminate clinical knowledge into practice. Elsevier is partnering with many large EHR vendors, providing them with clinical decision support plug-ins at the point of care. Elsevier has the clinical knowledge base and worldwide scale to disseminate the insights and systems developed during this project to practicing physicians. They are already focusing heavily on artificial intelligence, machine learning, NLP and have built a competitive IT division of over 1000 technologists.

Second, ExpertDoc developed an existing CDSS called NHGDoc. This system serves thousands of GPs in the Netherlands. Their product currently consists of clinical decision rules that are solely based on primary care guidelines to provide input (e.g. alerts and reminders) to GPs. ExpertDoc recognizes the opportunity in the increasing availability of digital data, algorithms, and computational infrastructure and the value of these in providing new data-based services to their clients. In this way, machine learning can potentially enhance evidence-based practice with data-driven statistics.

Last, Uw Zorg Online provides two main services to GPs: developing and maintaining websites for their practices, and facilitating patient portals. GPs and other healthcare providers offer a wide range of online services to patients through these systems. Uw Zorg Online is seeking ways to increase the value of their portals to both patients and GPs, hence their desire to collaborate. By answering scientific questions, the academic partners of the consortium will develop the knowledge and the technology in terms of the predictive models and the shared decision-making strategy to fulfil the needs of the private partners.

Collaborating with these parties is both valuable and challenging and resulted in some lessons learned that might be useful for future comparable projects. First of all, it is important to note that collaborating with external technological partners has been crucial for the successful development of our systems. Using their existing infrastructure allowed us to quickly implement a fully integrated CDSS, for instance. This sped up the development process and also makes possible future implementation in practice more realistic and efficient. However, there are, of course, also certain limitations that need to be taken into account. Not all of our original plans could realistically be implemented, so it is important to start the process with an open mind and a lot of flexibility. Also later on in the development process, certain issues that were raised concerning the prototypes could not be (fully) resolved because of the existing software that we were working with. Lastly, after developing and evaluating the intervention, it is very valuable to already be in contact with these partners. We are currently conducting a feasibility study with multiple relevant stakeholders (e.g. our technological partners, insurance companies, GPs) to create a blueprint for future implementation of the intervention.

Challenges
The broad, interdisciplinary nature of this project is very valuable, but also comes with certain challenges. Originally, we planned a seamless integration between the CDSS and the patient portal, meaning that these two systems would be able to communicate and information inserted by the patient would be sent directly to the GP's system. This integration was part of a larger national project which was postponed. This necessitated thinking of other solutions where we could still test the intervention without this strong integration. In the end, we opted for a simpler architecture: during the RCT, the patient is not invited through Uw Zorg Online's original patient portal, but through a new website that Uw Zorg Online designed specifically for the SNOWDROP project.

Recruiting older patients and, especially, GPs during and right after the COVID-19 pandemic, a time during which there is a large primary care backlog, also posed a challenge. GPs felt, and often still feel, overwhelmed and unable to participate in research. Even though four GPs expressed their intention to participate at the start of the project, in the end they were not able to. For the RCT, fortunately, not all GPs have to start at the same time, allowing us to recruit in a phased manner. The simpler architecture of the patient portal discussed above also presented an opportunity. Now that Uw Zorg Online built a separate website instead of using their original patient portal, practices that don't make use of the Uw Zorg Online patient portal are also eligible for the RCT. This allowed us to recruit from a larger pool of GPs.

From the technical perspective, our project involved the use of textual data (clinical notes) mainly to define the outcome “fall” as the coding system used by the GPs to encode diseases and symptoms does not contain a code to describe falls. Because of the necessity to inspect free-text data, there were inconvenient regulatory procedures in place to ensure privacy protection before acquiring the data. Furthermore, the development of our prediction model involved a manual chart review of the clinical notes to identify fallers, which was laborious and time-consuming. Another technical challenge was the need for a high performance computing environment to combine and analyze the data, especially to apply advanced deep learning algorithms and NLP techniques. Aside from computational demands, there is the important challenge of protecting the privacy of the patients. In this regard, exploring federated learning, where computations occur locally, and only their results are communicated (Zhang et al., 2021), presents a promising avenue for future research.

Further Steps

Although we have achieved key milestones, there are many opportunities for further research. As for the data science aspect (WP1), we will continue leveraging our data, machine learning and NLP to contribute to research and innovations related to falls in older people. Because falls are multifactorial and are a result of the dynamic interaction of risk factors, we will apply data-driven approaches combined with clinical experience to discover these interactions. By doing this, we hope to improve the predictive performance of our prediction model. Furthermore, the temporal ordering of the clinical notes in our dataset is a potential property that can be exploited in different ways. We will apply dynamic topic modeling to discover and isolate topics associated with falls as these topics evolve over time. The hypothesis is that certain topics are more represented in older people who fall and the prominence of these topics increases over time just before fall events. This will improve our understanding of the mechanism underlying falls and could discover potential predictors thereof.

In WP2, the ready-to-implement systems have been developed and are ready to be used in the RCT. This RCT is currently running, meaning that data collection has commenced, but results are not yet available. The next step is to analyze the data and see to what extent the intervention had an effect on our outcome measures. To investigate which steps have to be undertaken for real-life implementation, an additional feasibility study will be conducted. This feasibility study looks at the requirements for broader implementation of the intervention. We will examine how large-scale implementation of the intervention, first in

Amsterdam and then nationally, can be achieved. Several stakeholders, such as healthcare professionals and a private partner will be consulted during an interview study. The feasibility study will result in an implementation plan that can be used as a blueprint for future implementation.

Conclusion

All in all, the SNOWDROP project has achieved many key milestones and continues to do so. The prediction model has been created and validated, and the full intervention consisting of a CDSS and patient portal has been developed and is currently being evaluated in an RCT. The findings of the RCT will determine future steps of the SNOWDROP project. The learnings from this project as a whole and the architecture underpinned by predictive modeling to support both GPs and patients can also be applied to other major health problems in the future.